Supportive and palliative care for patients with COPD

Chronic obstructive pulmonary disease (COPD) is the most common respiratory disorder in the UK (Shee, 2001). In 1999, the number of people who died of COPD was equal to the number who died of lung cancer (Hill and Muers, 2000). Patients’ knowledge of the high level of morbidity of this disease has a large impact on their social, psychological and economic status (Addington-Hall et al, 1998). Patients with COPD, unlike those with lung cancer, may go from crisis to crisis, requiring many hospital admissions, and are more likely to die in hospital after an acute admission (Edmonds et al, 2001).

Case study  David Brown (not his real name) is a 65-year-old married man who was diagnosed with emphysema in 1995. He gave up smoking when diagnosed, and had previously been treated for asthma. He stopped working three years ago.

Mr Brown lives with his wife, who works part time, in a house he now finds difficult to leave – or even move around in – due to his acute breathlessness. He feels trapped. Mr Brown sees his GP whenever his condition deteriorates, and has attended his local district general hospital since diagnosis. He has been admitted to hospital three times in the past year with exacerbations of his COPD. His family take care of his physical and domestic needs.

He has been diagnosed with depression by his GP, who prescribed anti-depressants. At the time, he was poorly nourished and was experiencing panic attacks.

Mr Brown had not previously had access to a COPD nurse specialist and had never attended a pulmonary rehabilitation programme. Such programmes have been shown to improve the quality of life of people with COPD (Shee, 2001).

He was admitted to Papworth Hospital to optimise his medical management. He had been treated with antibiotics, bronchodilators, steroids and oxygen therapy in his local hospital and required further assessment. On admission, he was commenced on non-invasive positive pressure ventilation (NIPPV) to provide ventilatory support and alleviate the symptoms of breathlessness.

The medical and surgical teams talked to Mr Brown about lung volume reduction surgery (LVRS) and lung transplantation. He had pinned his hopes on surgery and/or transplantation and was devastated to discover that his condition was not suitable for either.

The aim was that Mr Brown would use the NIPPV system every night. He was tolerating the machine fairly well, but he found the reality of taking the machine home distressing. ‘This is not how I saw my life ending up,’ he said.

Assessment of supportive and palliative care needs  Mr Brown wanted active acute treatment. However, the nature of non-malignant, non-curable, life-threatening disease is such that death may be sudden even when end-stage disease is diagnosed (Addington-Hall and Higginson, 2001). Supportive and palliative care can, therefore, contribute to the active management of such patients alongside acute care (Box 1 and 2).

A palliative care approach takes into account the patient’s past life experience and current adaptation to his or her situation, with the emphasis on open and sensitive communication and the relief of suffering. The approach encourages the expression of individuality, assists empowerment and supports autonomy.

Palliative care has traditionally been available to patients and the families of those who have cancer. However, patients with severe COPD can experience an extremely poor quality of life and are often relatively disadvantaged in terms of medical and social care compared with patients who have lung cancer (Gore et al, 2000).

A therapeutic relationship is essential for the assessment of supportive and palliative care needs (Lugton and Kindlen, 1999). I became involved in Mr Brown’s care as a specialist nurse in supportive and palliative care for non-malignant disease. When we first met, he was relieved to have someone to talk to about how he felt, although he found talking extremely difficult due to his breathlessness.

Over the past year before we met, Mr Brown’s condition had deteriorated and he had withdrawn from most activities. He felt that his quality of life was now very poor and he was fearful for the future.

He had developed some coping strategies to deal with his situation but now he no longer felt in control. He had begun to recognise the full extent of his illness and to consider his mortality. Having managed to cope for so long, he and his wife were now feeling lost and in need of support.

He told me that very few people could understand how ill he was. ‘While I am sitting still and not doing anything, I look fine – my brain is still active,’ he said. ‘I don’t like to bother people. When you have to keep asking people to do things for you, they think you just can’t be bothered to do it for yourself.’

He talked about the strain his illness had caused in his relationships and finances, and about the grief he felt for the loss of the future he had planned.

The philosophy of supportive and palliative care also extends to patients’ families. Mr Brown’s wife was glad to

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REFERENCES

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A palliative care approach, alongside acute intervention, is essential for patients and their families dealing with end-stage chronic obstructive pulmonary disease (COPD). The support of a multidisciplinary team, working with specialist palliative care services, can improve quality of life for these patients. Sarah Morgan reflects on the care of a patient with COPD, which highlighted the need for supportive and palliative nursing.

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be able to discuss the feelings she had. She was fearful of being disloyal to her husband and kept many of her feelings from her family and friends. She felt she had become exhausted and found herself wishing she could just ‘get away from it all’. She and her husband needed help to talk to each other honestly about how they felt.

Both had been trying to protect the other from being hurt and had stopped communicating openly about how they were feeling, despite having always shared their feelings in the past.

Supportive and palliative care interventions
Supportive and palliative care interventions need to be instituted early in the course of the disease to support disease management and to help the patient develop coping strategies, which will benefit overall quality of life (Gore et al., 2000).

The use of programmes such as pulmonary rehabilitation and the use of outreach nurses have been shown to improve quality of life for patients with moderate COPD (Shee, 2001). The recognition of the need for supportive care earlier in the management cycle may have helped Mr Brown and his family to address issues regarding treatment choices and helped them to cope better with the progression of his illness.

I saw Mr Brown throughout his hospital stay and, acting as a specialist resource in symptom control management and in supportive care, it was possible to ensure a palliative care approach was applied alongside his acute management.

Mr Brown was also seen by a social worker who helped him apply for financial benefits, and a physiotherapist and occupational therapist, who provided additional practical advice on breathlessness management and domestic aids to assist independence.

When he was discharged, I liaised with the hospital respiratory nurse specialist and district nurse, who supported him locally.

With support, Mr Brown was helped to begin the task of facing his situation and confronting the choices that were available to him. Many patients with COPD do not have access to such services, even in the later stages of their disease.

Conclusion There is increasing recognition that patients with non-malignant, non-curable, life-limiting disease need supportive and palliative care, but there are currently too few specialist services available (Addington-Hall, 1998).

Specialist nurses, working in areas such as respiratory disease, heart disease and community nursing, are well placed to develop their skills in supportive and palliative nursing. They have the opportunity to promote the application of palliative care philosophies within the field of non-malignant disease, but they need specialist training and education.

The provision of supportive and palliative care, alongside acute treatments and chronic management of non-curable, non-malignant respiratory disease will undoubtedly improve the quality of care and quality of life for people living with and dying of COPD.

**BOX 1. PALLIATIVE CARE**

Palliative care is an approach that improves the quality of life of patients and their families who are facing the problems associated with life-threatening illness. It offers prevention and relief from suffering by means of early identification of pain, and its assessment and treatment, as well as that of other physical, psychosocial and spiritual problems. Palliative care:

- Provides relief from pain and other symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if this is required;
- Will enhance quality of life of the patient, and may also positively influence the course of illness;
- Is applicable early in the course of the illness, alongside other therapies that are intended to prolong life, such as chemotherapy or radiation therapy. Palliative care also includes any investigations needed to better understand and manage distressing clinical complications.

(National Council of Hospices and Specialist Palliative Care Services, 2002)

**BOX 2. SUPPORTIVE CARE**

Supportive care is designed to help patients and their families to cope with non-curable disease and its treatment. This care includes diagnosis and treatment, which results in improvement, continuing illness or death. It also covers bereavement. It helps patients to maximise the benefits of treatment and to live as well as possible with the effects of the disease (National Council of Hospices and Specialist Palliative Care Services, 2002).

**REFERENCES**


**USEFUL WEBSITES**

The British Lung Foundation has produced an extensive range of information booklets and fact sheets for people with lung disease. The foundation provides practical support through the Breathe Easy Club, a national network of voluntary local support groups. Groups consist of people of all ages who have lung conditions and their carers, families and friends.

Publications can be obtained by calling the leaflet information line on 020 7831 5831. Leaflets can be downloaded from the BLF website: www.lunguk.org.

Smoking cessation Two useful websites for advice on smoking cessation are www.quit.org.uk and www.ash.org.uk. The NHS Smoking Helpline (0800 1690169) can provide advice and support on stopping smoking, an information pack and the details of local NHS stop-smoking clinics.

www.nursingtimes.net