The psychological needs of patients with chronic respiratory disease

Recent developments in medical management have improved symptom control and life expectancy of patients with chronic respiratory disease (CRD). However, this presents new challenges to patients, their relatives and friends, and health professionals.

Incidence of CRD has been linked to socioeconomic status. For example, men in unskilled, manual occupations are 14 times more likely to have chronic obstructive pulmonary disease (COPD) than men in professional occupations (British Thoracic Society, 2000). Although the impairment and disability associated with CRD has been recognised (Williams and Bury, 1989), CRD still has a low public profile. As a result, the cost to people with CRD and their families is often unrecognised, and psychological needs may not be specifically targeted.

For example, people with end-stage respiratory disease have a significantly impaired quality of life, but their needs are not as well met as those of people with cancer (Gore et al, 2000). The palliative care needs of people with CRD are poorly understood and under-researched. It is possible to suggest that this situation is exacerbated by the lack of a respiratory national service framework, and by current guidelines, which emphasise medical rather than holistic management (Global Initiative for Chronic Obstructive Lung Disease, 2001; British Thoracic Society, 1997).

The effect of CRD on morbidity and mortality

When people are told they have developed a chronic respiratory condition, they may need to make a number of behavioural, social and psychological adjustments. Inevitably, the impact of diagnosis changes the way patients view themselves, their lives and the future.

The graph shown in Fig 1 is often used by respiratory nurse specialists to help describe the effect of COPD to patients. It is also used to illustrate that smoking cessation can be beneficial even if patients have advanced symptoms.

However, the graph shows life expectancy is severely reduced once patients have presented with disabling symptoms, even if they manage to stop smoking.

Living with CRD

Patients and their relatives can be affected in many different ways. Patients will face many daily challenges, including a change in lifestyle. The way they adjust to their disease will determine their coping strategies.

Factors that will influence this adjustment include age, the individual’s role in the family, employment status, financial problems, poor mobility, social isolation, and loss of sexual identity and independence.

Some patients, despite daily frustrations and challenges, seem to adjust well and remain optimistic. However, others find adjustment less easy, and often employ inappropriate coping strategies that can compound their problems. The result is a variation in quality of life between different patients with the same condition (Britton, 2003).

Patients with CRD often have to cope with a changing body image, and embarrassment from dyspnoea (shortness of breath), coughing and sputum production. These problems can result in a sedentary lifestyle with progressive dyspnoea and fatigue, often resulting in increased social isolation.

Guthrie et al (2001) interviewed patients with CRD and found that anxiety, fear of death, and social isolation were major issues for them. By recognising these problems, health care professionals can help patients to manage their illness more effectively.

Assessment

A range of validated tools for measuring quality of life is available. These are often generic measures of health status but some disease-specific tools are available and have been evaluated (Singh et al, 2001).

The St George’s Respiratory Questionnaire (SGRQ) (Jones et al, 1992) is a popular but lengthy questionnaire, so it is usually reserved for research purposes. A shortened version of the SGRQ is available, which measures health status rather than assessing the psychological impact of a respiratory disorder.

There are also a number of validated psychological assessment scales, such as the Acceptance of Illness Scale (Weinman et al, 1984) and the Hospital Anxiety and Depression Scale (Snailth and Zigmond, 1994). Assessment scales can require patients to focus on...
issues such as dependency on others, and feelings of hopelessness, uselessness and inadequacy. Caution must therefore be exercised when using such scales, and any issues raised should be addressed.

**Interventions**

**Access to social services** This is difficult for patients with respiratory disease as their disability is often insidious. For most patients, dyspnoea is the main cause of their loss of mobility and independence, but it is seldom seen as a disability. As a result, many patients do not claim financial benefits they may be entitled to.

Also, the length of the forms used to claim benefits can be off-putting, and patients may need help to complete them. The provision of a disabled parking badge can have a substantial impact on lifestyle.

**Breathing and activity** Activity intolerance can be addressed by exercise and energy conservation techniques. These aim to enable patients to increase activity to their full potential, within the limitations imposed by their disease, and to improve quality of life (Morgan and Singh, 1997).

Dyspnoea, although a physiological response, can be described as a subjective phenomenon and there can be significant disparity between patients’ perception of disease severity and objective lung function (King and Cotes, 1989). Also, anxiety has been closely associated with dyspnoea (Hodgkin et al, 1993).

Teaching effective breathing patterns and airway clearance techniques can reduce the fear of dyspnoea, reduce the work of breathing and increase confidence.

**Pulmonary rehabilitation** Many of these interventions can be delivered collectively in the form of a programme of pulmonary rehabilitation. This type of rehabilitation is increasingly recognised as an important part of the management of CRD, in particular COPD.

The principal goals of pulmonary rehabilitation are to reduce symptoms, decrease disability, increase participation in physical and social activities, and improve overall quality of life for patients (BTS, 2001).

It aims to address the downward spiral of disease, when a patient’s dyspnoea can result in activity avoidance, deconditioning and subsequent functional impairment. This in turn leads to loss of confidence, and the fear of dyspnoea being perpetuated by anxiety and depression.

Pulmonary rehabilitation can prove invaluable in helping patients adjust to living with CRD, improve their exercise tolerance and combat social isolation.

**Support groups** ‘Breathe Easy’ groups organised by the British Lung Foundation can also help reduce social isolation and foster mutual support. These groups are run with the help of patients, and often feature speakers and education sessions within the meetings.

**The role of health care professionals** The ability to understand patients’ feelings is a crucial part of the role of health professionals, and patients should be given permission to talk about the psychological impact of their disorder. The use of strategies such as open question sessions and active listening techniques can help to achieve this.

It is often difficult to decide when to refer a patient to a specialist, and this decision can be influenced by the health professional’s own skills. However, there will be times when it is appropriate to utilise resources that are available. In terms of psychological problems, the two main agencies that patients can be referred to are psychiatry and clinical psychology.

Interest is growing in the use of some psychotherapies for patients with CRD. For example, cognitive behavioural therapy is one approach that is being assessed.

**Campaigning for better services** CRD can be perceived as unglamorous and, in some cases, self-inflicted. Respiratory illness does not have the same public image and charity funding status as other illnesses, and as such can be seen as one of the greatest challenges for future health care provision.

There is much that can be done to improve patients’ quality of life, and health care professionals can work together to help patients manage their illness more effectively.

Recent data has highlighted the substantial burden that respiratory diseases impose on the UK’s population and health care services, and the gross underprovision of resources (Chung et al, 2002).

The Respiratory Alliance is a group of respiratory charities and professional bodies dedicated to campaigning for better services for respiratory patients. Its publication, Bridging the Gap (Respiratory Alliance, 2003), highlights the lack of a national strategy and a national service framework.

The alliance claims that putting patients with CRD at a disadvantage may lead to potential discrimination against them in terms of health care provision.

It is the responsibility of every health care professional involved in the care of patients with respiratory disease to raise awareness of the psychological impact of CRD, and of the need for adequate provision of services to treat and support these patients.

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