Psychological effects of chronic lung disease

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Abstract

Carol Kelly and Dave Lynes outline the potential psychological consequences of living with a chronic respiratory disease and how nurses can assess problems and implement strategies to help patients to adjust and cope.

Identification and management of the physical signs and symptoms of chronic lung diseases (CLDs) has improved but the psychosocial burden is often unrecognised and neglected.

CLD can involve a gradual and progressive decline in lung function which results in increased dyspnoea and reduced ability to perform daily activities. It also involves alterations in the person’s social roles, relationships and self-perception so demands continual psychological adjustment.

If patients are to live with chronic disease and maintain a good quality of life, it is imperative that these issues are not only recognised but also managed.

What is chronic lung disease?

CLD refers to any lung pathology that has an underlying chronic nature, in other words, disease that cannot be cured and which tends to worsen over time.

COPD is progressive. Its physical and psychological effects on the individual increase. Asthma may not result in an inevitable decline in health status but can be difficult to control. The aim of asthma control is to prevent symptoms from occurring; failure to do this may result in significant disability.

Asthma and COPD are the most common chronic respiratory conditions in the UK. The term CLD also includes other diseases, such as bronchiectasis, pulmonary fibrosis and cystic fibrosis (CF).

Physiological effects of CLD

The physiological signs and symptoms of CLD are common to most lung pathologies and can have a profound disabling effect on patients. Symptoms frequently include dyspnoea, cough and production of sputum.
Dyspnoea (breathlessness) can be chronic and disabling and it can worsen considerably during exacerbations of the disease. Brownrigg (2007) reported on his personal experience of living with COPD. He described how dyspnoea resulted in considerable modifications in his lifestyle, such as careful planning of outings and holidays to avoid crowds, hills and stairs. Some of his descriptions of living with COPD are summarised in Box 1.

Box 1. Living with COPD

- ‘If there are any slopes or hills, you’re scuppered’
- Exacerbations are ‘terrible’ resulting in ‘a complete loss of breath’
- ‘It felt like I simply could not breathe in. I was looking at the nurses and the doctors, but I could not speak and I was hanging on the doorway and trying to control my panic. I thought that the staff were not taking it seriously and it was making me panic.’
- ‘If you want to imagine what it is like to have an exacerbation, pinch your nose and close your mouth and see how long you can do that before you panic. Don’t give up when you feel like giving up, keep going until you become desperate and panic. If I was in a situation where I could not get help quickly, that is how I would feel; I would feel this desperate panic. So if a patient is on a ward and they say they need help, this does not mean that they need it in an hour’s time; they need it there and then.’

Source: Brownrigg (2007)

The American Thoracic Society (1999) described dyspnoea as ‘a subjective experience of breathing discomfort’. This suggests that it is what the patient feels and does not necessarily correlate with lung function or disease severity.

Dyspnoea is a very complex phenomenon, with patients experiencing a mix of physiological, psychological, social, environmental and behavioural responses. Therefore, it follows that successful treatment of dyspnoea should not be restricted to bronchodilators or other physiological interventions. Collectively, the experiences of physical symptoms, the chronic, persistent nature of these symptoms and the degenerative trajectory of disease all contribute to psychological responses that impact on patients’ quality of life.

Psychological effects of CLD

The effect of living with CLD is very individual. While some patients may seem to adapt well, others find the experience devastating.

The consequences are far reaching, from altering day-to-day living to influencing a person’s overall outlook on life. Some of the possible psychological consequences are listed in Box 2.

Box 2. The experience of living with chronic lung disease

- Stress and anxiety
- Depression and low mood
- Fear of dying/breathless/exacerbation
- Panic
Expression of emotion is closely linked with dyspnoea and some patients may avoid emotion as an adaptive coping mechanism. This may result in patients living in an ‘emotional straightjacket’ (Dudley et al, 1980), which may then predispose to or compound existing anxiety and depression.

Impaired physical and social dimensions of daily living often result in a sedentary lifestyle with progressive dyspnoea and fatigue. This in turn leads to social isolation and an inability to participate in many activities of daily living.

**Research into psychological effects of lung disease**

Research into the psychological effects of living with CLD demonstrates that patients with respiratory disease often fare worse than patients with cancer (Gore et al, 2000).

Guthrie et al (2001) noted that patients reported confronting issues of:

- Changing body image;
- Embarrassment (from dyspnoea, cough and sputum production);
- Change in the social position within the family (where they were the main breadwinner);
- Inability to work;
- Financial implications of their disease;
- Poor mobility;
- Social isolation;
- Loss of sexual identity;
- Loss of independence.

These changes are part of a gradual transition to dependence and inevitably altered family dynamics, which has the potential to contribute to the development of resentment and tension.

Often these psychological costs are evident early in the disease pathway before symptoms start to affect daily activities and lifestyle.
Arne et al (2007), using grounded theory, interviewed patients with COPD to explore their perspectives at the time of diagnosis. Shame proved to be a main theme and was related to the notion that their disease was self-inflicted and this was an obstacle when seeking advice. This idea of psychological impact early in the disease trajectory may suggest that the psychological morbidity could be equal to or even greater than the effect of early physical symptoms themselves.

As a result of this morbidity, patients will often describe themselves as ‘being a burden’ and, particularly where they have COPD, also experience a sense of guilt. This can be caused by several factors including a history of smoking and the impact that their disorder has had on their family life (Robinson, 2005).

Even patients who have never smoked – for example those with chronic asthma – may experience some stigma attached to the fact that they have a disease that involves cough and phlegm. This stigma in turn may contribute to negative attitudes from the general public and professionals alike.

Carers may experience psychological problems similar to those identified in Box 2. They describe stress in relation to feeling restricted, anxious and profoundly helpless in the face of dyspnoea, accompanied by a sense of preoccupation with their relative and a debilitating hypervigilance (Booth et al, 2003). Booth et al (2003) describe them as ‘invisible victims’, listening, watching and waiting.

This alteration in relationships can impact on family dynamics and some patients see quality of life as depending on family relationships (Guthrie et al, 2001). Family and social networks have been shown to have a positive effect on the patients’ quality of life and health outcomes (Wang and Bourbeau, 2005).

Carers’ and patients’ perceptions of the disease burden is important when determining their coping abilities – indeed, this perception can be more important than the disease itself. A feeling of control or sense of mastery over the disease is an important aspect of coping with chronic symptoms.

Patients also experience fear, particularly fear of breathlessness, death and dying. Shackell et al (2007) found that patients’ anxiety and fears of breathlessness and dying, extended into the night and were aggravated by feelings of isolation, vulnerability and frustration. One patient reported that they often thought ‘am I going to see the next morning?’.

This fear and sense of helplessness can lead to panic and evidence suggests that patients with chronic breathlessness often call for emergency assistance during the night (Booth et al, 2003).

Much of the evidence explored so far relates to COPD. While other CLDs have received less attention, evidence suggests that patients with pulmonary fibrosis experience negative feelings associated with depression, which in turn affect their quality of life (De Vries et al, 2001).

Asthma that is difficult to control has been acknowledged as causing psychological morbidity in the updated British Thoracic Society/Scottish Intercollegiate Guidelines Network
guidelines (BTS/SIGN, 2008). These recommend routine assessment of coexistent psychological morbidity.

The life expectancy of people with CF has increased considerably in recent years and, as a result, issues such as quality of life and psychological well-being, previously thought to be of lesser importance than physical well-being, are now recognised as important factors.

Research into CF is scarce but there is a suggestion that adolescents with CF appear to be a psychologically well-functioning and well-adjusted group (Szyndler et al, 2005). It is possible that this may be as a result of a more comprehensive healthcare network or just that they have ‘grown up’ with the disease and therefore adjustment is more natural.

Adolescence is a period of transition to independence from parents and the development of a unique identity, during which the opinions and behaviour of peers often have more influence than family.

Delambo et al (2004) report that positive family relationships have the potential to contribute to the emotional well-being and adjustment of the adolescent with CF. Poor adherence to treatment is associated with brittle family relationships characterised by conflict.

**How can nurses identify where lung disease has a psychological impact?**

Despite the high incidence of psychological effects it has been reported that 82% of patients with COPD received no treatment for depression (Elkington et al, 2005). A survey of patients found that they focus on feeling unwell, their ability to perform everyday activities and on the emotional consequences of the disease. Doctors, on the other hand, focus on physical functions and measuring clinical symptoms (British Lung Foundation, 2006). Nurses can be central in communicating with patients and focusing and highlighting what is important to the patient.

**Assessment tools**

Several tools for assessing psychological morbidity exist. These are either generic, for example the Hospital Anxiety and Depression score (HADS) (Snaith and Zigmond, 1994) or the Geriatric Depression score (Yesavage et al, 1983), or they can be disease specific. Disease-specific tools generally focus on aspects of CLD that affect health-related quality of life (HRQL). Examples include the Chronic Respiratory Disease Questionnaire (Guyatt et al, 1993) or the St George’s Respiratory Questionnaire (Jones et al, 1992).

There are potential drawbacks to using any of these tools in clinical practice. Questionnaires take time to complete and this can lead to healthcare professionals selecting self-administered versions. However, self-administered tools can have pitfalls, for example a question may be misunderstood. Nonetheless, obtaining some degree of objective assessment can help in identifying co-morbid psychological problems.

If problems are identified, it is imperative that patients are managed or referred to other services.

**Assisting patients to adjust and cope**
Any strategies that can enhance coping abilities and relieve symptoms will ultimately be of benefit to patients.

Psychological interventions for the management of dyspnoea include techniques such as distraction therapy and relaxation. There is evidence that dyspnoea can be more effectively managed if it is addressed as a multidimensional concept that includes the emotional experience of breathlessness as well as consideration of the causative biological mechanisms (Corner and O'Driscoll, 1999).

Fears can be addressed through good communication and involving the patient and their families in decision-making. This enables the patient to feel more informed and in control.

Pharmacological approaches are valuable in treating depression, panic attacks and insomnia, and include the use of anxiolytics and opioids (Jennings et al, 2001) and oxygen for relief of dyspnoea (Booth et al, 2004). The use of oxygen does however have drawbacks, including being a barrier to communication, causing dryness of the mouth and, in some patients, worsening hypercapnia giving rise to headaches, drowsiness and even acute respiratory failure. Careful assessment is therefore required before it is prescribed for non-hypoxaemic patients (Kelly and Lynes, 2008).

Non-pharmacological approaches, such as cognitive behavioural therapies (Parkin et al, 2006; Heslop and Rao, 2003), have also been found to be effective with patients with COPD and bronchiectasis.

*Coping strategies and education*

Patients often develop their own coping strategies and these should be encouraged.

Fraser et al (2006) conducted a phenomenological study assessing the experiences of patients with COPD and how the disease has affected their lives. The researchers suggested that patients have extensive experience of managing their diseases and are familiar with techniques that help integrate symptoms into their lives. By listening to patients, nurses can draw on their own knowledge and the patients to help them achieve maximum quality of life. Simple patient-centred goal-setting can often facilitate this process and enable patients to adopt a more positive outlook through a sense of achievement.

Education of patients is important to promote aspects of self-management, such as early identification and intervention for exacerbations. This in turn nurtures self-efficacy: a belief about the patient’s capability to influence events. Self-efficacy determines how people feel, think, motivate themselves and behave.

*Pulmonary rehabilitation*

Pulmonary rehabilitation aims to maximise functional ability. It has been shown to increase HRQL, increase self-efficacy, decrease psychosocial morbidity and it has a positive impact on self-esteem (American Thoracic Society/European Respiratory Society, 2006).

Some of its benefits are derived from peer interaction where patients can learn from each other. It may also help the patient to ‘rethink’ their illness if they learn that they can exercise and become breathless in a controlled environment.
Social care
Social care affects how patients adjust and make sense of their illness. They may have financial problems because they have been unable to work and addressing financial concerns may allay some anxieties. This can have a positive impact on carers.

Palliative care
Most patients with CLD require a palliative care approach to the management of their symptoms and lifestyle. This will encompass psychological care that enables them to express thoughts, feelings and fears.

End-of-life care is important and addressing concerns proactively at an appropriate time can be beneficial. By allowing patients the opportunity to discuss specific issues, for example where they would like to die, can help alleviate anxieties and give patients a sense of control. The use of Preferred Priorities of Care plans can assist with this and offer an alternative to the reactive approach often seen in hospital settings.

Conclusion
The impact of living with a CLD can have tremendous psychological consequences for patients, families and carers. Psychological well-being is very important and therefore assessment and support of patients is central to management.

For many people with CLD, the experience of care involves a reactive approach focused on physical symptoms and acute exacerbations. This often results in neglect of psychosocial problems and inappropriate management strategies, often involving multiple readmissions. It is essential that healthcare staff understand and address these psychological aspects of disease so that patients and carers can be supported to live with their CLD.

References


