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EDITORIAL

Too little, too late – the patients' perspective on education for COPD

There are two main reasons to educate people with chronic obstructive pulmonary disease (COPD) about their condition: firstly, to allow them to understand how the disease affects them and, secondly, to understand how to develop the best strategies to cope with their disease. People with COPD wish to know what is happening to their bodies now and what will happen in future.¹ With knowledge and understanding, they produce a contextual framework through which they can interpret their symptoms and the expectations for the future. The second reason is so they can change their behaviour to improve their 'lot' – in particular, adapting their habits in terms of smoking, exercise and managing changes in their condition.²

Behaviour change is central to outcome in people with COPD. For instance, breathlessness and exercise limitation relate as much to physical deconditioning as the degree of airflow obstruction,³ and lack of fitness can be improved by taking more exercise.⁴ Smoking cessation improves outcomes in terms of lung function and mortality.⁵ Equally, dietary changes improve prognosis in those who are underweight.⁶ Active management of exacerbations using medication and exercise ameliorates the impact of an exacerbation.^{7,8} Receiving and adhering to treatment with appropriate inhaled medication will have benefits as inhaled and steroids long-acting bronchodilators improve symptoms, exacerbations and reduce decline in lung function.^{9,10}

The problem is that education programmes alone do not produce much by way of behaviour change; nor do they improve quality of life, symptoms, activity levels or health care consumption.^{11,12} To change behaviour, education needs to do more than inform; it must address the patients' perception that a change in behaviour is both necessary and beneficial.¹³ In pulmonary rehabilitation, education is provided in an integrated programme with exercise and psychosocial inputs, and pulmonary rehabilitation is very successful in improving quality of life, exercise capacity and other outcomes.¹² Thus the best way of delivering education may be as part of an integrated programme involving behaviour change models such as pulmonary rehabilitation.

Although a lot of research has been conducted on the optimum exercise regimes in pulmonary rehabilitation, little work has been published on the optimum education component. The key components of education in pulmonary rehabilitation have been described in guidelines and consensus statements.^{4,9,14} The topics for patient education were selected by a panel of expert clinicians; perhaps, a more appropriate source of expertise is from patients. In their paper, Rogers *et al.*¹⁵ report the findings of a qualitative study on information needs of patients attending pulmonary rehabilitation, which, for the first time, provides the patients' perspective. Patients who had attended pulmonary rehabilitation were asked about their information needs, an approach which has the advantage of using an enlightened group who are able to look back to their learning needs before the programme. Several key themes emerge: general lack of information about their condition, how the rehabilitation process should deliver education and the importance of continued support after the programme.

This study clearly shows the patient's lack of basic information about their condition, such as importance of having a name for the condition which they and others recognize. Prior to rehabilitation, the patients reported having little understanding of the disease process and its management. In particular, primary care was criticized as a poor source of expertise, information and support. These findings are similar to several previous studies.^{1,2,16,17} Furthermore, the timing of education is important: patients in this study want the information at the point of diagnosis. This is not just a comfort factor as the benefits of behavioural change, such as smoking cessation, diminish as the disease progresses.⁵

COPD carries a very high burden of symptoms and progressive decline – for many it is a life sentence. Many sufferers carry guilt that they caused their own problems and may receive little sympathy. Sometimes health professionals add to their guilt, but Rogers *et al.* indicate that in pulmonary rehabilitation, patients appreciate working with supportive staff. To deal with

their emotional stresses, the patients suggested that individual counselling could be arranged within the context of pulmonary rehabilitation. While this idea merits further consideration, many programmes already include a session by a counsellor or psychologist, which was not the case in this study. Patients were able to make effective gains during the programme, but maintaining the gains in the long term was a problem, especially with a six week course without further support, 'You've had somebody sort of caring for you for six week and them being interested in you and then it's just gone you know'.

Given that education is critical to effective pulmonary rehabilitation, objective measures of the impact of the education component are needed to assess the quality of a rehabilitation programme. Pulmonary rehabilitation knowledge questionnaires test the knowledge of patients and are predicated on clinicians perspective of what is important. They tend to be long – the Bristol COPD Knowledge Questionnaire has 65 questions¹⁸ and the Pulmonary Rehabilitation Knowledge Questionnaire has 40 questions.¹⁹ Information needs questionnaires, such as the Lung Information Needs Questionnaire, assess the patients' perspective of what they feel they need to know.¹ This questionnaire has 16 questions and is applicable to various different settings including pulmonary rehabilitation. Research is needed to examine the benefits of different forms of education on patient knowledge and behaviour change using validated outcome measures. Such research will help to establish how best to provide education including systems of delivery, contents and effectiveness for all patients with COPD.

The paper by Rogers *et al.* builds on a range of data indicating that COPD is a deeply unpleasant disease to suffer. Patients wish to have an early accurate diagnosis, education to allow them to cope intellectually, emotionally and to function socially. It is not much to ask, especially when these measures should reduce the burden on the health service. It is to be hoped that the forthcoming National Service Framework in UK will specify measurable quality requirements that will deliver better care for COPD patients and those close to them.

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