This is a summary: the full paper can be accessed at nursingtimes.net

PATIENT EXPERIENCES OF PULMONARY REHABILITATION

AUTHOR Deirdre Denn, MSc, RGN, Dip Professional Studies in Nursing, Dip Asthma Care, is respiratory specialist nurse, Cornwall and Isles of Scilly PCT.


This qualitative study used focus groups to explore patients’ understanding and expectations before, and their experiences after, attending a pulmonary rehabilitation programme. It found that the programme empowered participants to understand and cope with their condition and had an important social aspect.

BACKGROUND
Pulmonary rehabilitation aims to help patients manage COPD. There is no consensus on the best method for running such programmes – only that they should consist of exercise and education – but they have been shown to reduce hospital bed days (Griffiths et al, 2000).

Clark (1996) advocated using a group format with a multidisciplinary healthcare team to deliver education and exercise. In Cornwall, nurse-led community pulmonary rehabilitation programmes adhere to British Thoracic Society (2001) guidelines and are run once a week for nine weeks.

This study aimed to explore patients’ understanding and expectations before, and experiences eight weeks after, taking part in a pulmonary rehabilitation programme. For the literature search visit nursingtimes.net.

METHOD
A respiratory nurse and physiotherapist invited a convenience sample of 10 patients with COPD (four men and six women) to participate in the study. Five accepted the invitation.

Participants were asked to discuss issues surrounding pulmonary rehabilitation before the course in the first focus group, and the data was tape-recorded. A semi-structured question was followed by other pre-planned questions. The session lasted for a total of 45 minutes. Participants then took part in an eight-week exercise and education programme, and were asked to attend the second focus group on week nine. Due to the death of one participant, only four took part in this session, which lasted for 60 minutes.

The audio tapes were transcribed verbatim and analysed for emerging themes. These reflect the physical and emotional problems of living with COPD.

RESULTS

Focus group 1 themes
Stoicism: Despite knowing COPD is incurable, there was a sense of acceptance and a feeling that they should make the most of it. Participants were able to adapt to their physical limitations and were not prepared to ‘give in’ to simple tasks such as taking washing out of the machine or walking up a flight of stairs. They mostly coped by becoming frustrated until they completed their task, when they felt a sense of achievement.

Surprisingly, a COPD exacerbation leading to a hospital admission and discharge was seen as a positive event, almost as if participants had escaped death. One who had been admitted four times always felt better afterwards.

Respondents felt they could control their breathing by overcoming their fear of breathlessness. Some were surprised how much they had achieved on a baseline walk test. One characteristic was to view breathlessness as a challenge and adapt in the best way possible, for example by leaning on a supermarket trolley while shopping and asking for help to reach high items.

Impact: Most participants accepted smoking as a primary cause of their COPD, but expressed a sense of bereavement rather than anger or resentment about cigarettes. All had been advised to stop smoking and most had done so. However, one participant worked as a welder and was not convinced that his COPD was due to cigarettes. Others agreed that smoking should not be blamed entirely for their COPD.

It was difficult for participants to deal with the loss of being able-bodied and accept that they were unable to undertake certain tasks. They viewed COPD as a depressive and restrictive illness which robbed them of simple and enjoyable tasks and hobbies. Some had adapted to changes, for example by moving to a bungalow. The ability to keep some normality in life was alluded to.

Fear: Participants highlighted several factors that caused fear and anxiety. In particular, they were apprehensive about the weather, particularly heat. Only one

IMPLICATIONS FOR PRACTICE

Participants were optimistic that the programme would help them overcome the physical barriers they faced.

Pulmonary rehabilitation has an important social aspect, enabling patients to accept and live with their condition.

‘Streaming’ exercise can encourage patients to work to their maximum capacity and does not necessarily prevent them from working together.

Follow-up sessions after such programmes should be offered.

Having completed a pulmonary rehabilitation scheme, patients should be encouraged to establish a patient-led support group.

Further research would be useful to investigate whether pulmonary rehabilitation offers the same level of support to carers as patients.
Focus group 2 themes
Emergent themes from the second focus group reflected the physical, educational and emotional elements of taking part in a pulmonary rehabilitation programme.

Comradeship: Pulmonary rehabilitation involves physical exercise specifically intended to induce breathlessness in order to teach coping strategies. Patients can find this frightening and try to avoid the unpleasant experience of dyspnoea.

The support participants gained from each other during physical exertions resulted in a ‘clique-like’ attitude, since it is difficult for healthcare staff to appreciate the physical demands of pulmonary rehabilitation.

Peer support was evident in helpful suggestions, for example, one participant was angry that he could not stop smoking. The others encouraged him to keep trying, giving examples of how they or their friends had managed to stop.

Participants saw the group format as an appropriate way to deliver pulmonary rehabilitation. They regarded its physical element as a competition, which allowed them to ‘egg each other on’ and encouraged them to achieve their potential. They enjoyed being in each others’ company and were disappointed that the programme had ended.

Empowerment: Participants appeared more able to accept their condition. All felt it had given them confidence to live more active lives. One expressed his delight at being able to tell his daughter he went to the gym once a week.

Participants found education important and described the advice they received as relevant and delivered appropriately. However, gaining knowledge also enabled them to give themselves permission to ignore medical advice when it suited.

On the whole, respondents had greater control of their lives and better understanding of their condition. They were less likely to panic about breathlessness, and found the breathing exercises helpful.

Concept of severity: COPD is regarded as a ‘hidden’ condition, since patients only become breathless on exertion. This causes concern for some who feel they are regarded as not having an illness. They said that doctors should be made aware of the severity of their condition and how much pulmonary rehabilitation changed their view of coping with it.

The exercise element of pulmonary rehabilitation is not meant to be competitive; however, participants appeared to see it as a competition. The exercise circuit was separated into two lanes, which they named ‘fast’ and ‘slow’.

Although participants recognised there are different levels of severity of COPD, several expressed surprise at group members who did not appear disabled by their breathlessness. One felt some patients may use COPD as an excuse to avoid physical exertion, although others disagreed.

DISCUSSION
This small study explored patients’ understanding and expectations before and experiences after pulmonary rehabilitation. Before pulmonary rehabilitation, the three themes highlighted the importance of living with the physical and emotional aspects of COPD. Participants viewed an exacerbation as a challenge to be taken on and overcome.

Ex-smokers experienced distress and bereavement at having to stop. None blamed smoking entirely for their condition and felt it was unfair of healthcare professionals to single this out, especially as they thought occupational factors may play a major role. The only self-blame they expressed was the inability to prevent family members from smoking.

Depression and anxiety are recognised complications for some people with COPD but are not always appreciated as major causes for concern. Participants’ fear of loss of control filled them with dread.

The camaraderie and peer support generated by the programme enabled participants to identify ways of coping with a long-term condition and to overcome difficulties of physical exertion. The programme was described as enjoyable, highlighting the important social element.

Participants indicated that the knowledge they gained about both physical and practical management had enabled them to cope with their disease, and felt the physical aspect had increased their exercise capacity and confidence.

A relaxed and informal style of delivering education appeared important for participants; they enjoyed the use of anecdotes to illustrate educational topics and felt comfortable in questioning if they needed clarification.

Participants expressed concerns they would be regarded as fraudulent if they did not appear ill. They were keen to justify their physical problems to each other and healthcare professionals.