

Education in Pulmonary Rehabilitation: The Patient's Perspective

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Objectives: To ascertain from patients' perspectives what should be included in the educational component of pulmonary rehabilitation and how it should be delivered, and to compare those perspectives with the views of health professionals.

Design: Qualitative research method using focus groups of patients and health professionals.

Setting: A regional respiratory center and outpatient clinic.

Participants: Purposive samples of 32 patients with chronic obstructive pulmonary disease (COPD) (forced expiratory volume in 1 second, 18%–67% predicted) divided into 6 focus groups; 8 health professionals knowledgeable about COPD and pulmonary rehabilitation who attended a multidisciplinary focus group meeting.

Interventions: Participants attended focus group meetings (2–3h) guided by a series of questions and topics; results were posted to the participants for their verification.

Main Outcome Measure: The educational content of a pulmonary rehabilitation program.

Results: Deficits in patients' knowledge, understanding, and management of their disease were identified. Six key educational topics resulted: disease education, management of breathlessness, management of an exacerbation, medication, psychosocial support, and welfare and benefits systems. Patients and health professionals preferred group information sessions provided by knowledgeable people speaking layman's language, with oral presentations being supplemented by written information.

Conclusions: Gaining a greater understanding of patients' educational needs permits health professionals who design pulmonary rehabilitation programs to include these requirements in a format that is acceptable to patients. The key topics, content, and format for delivery of the educational component for pulmonary rehabilitation were identified. Future research should focus on the development of an educational package and assessment of its efficacy, which would facilitate equitable patient access to education in pulmonary rehabilitation.

Key Words: Education; Focus groups; Pulmonary diseases; Rehabilitation.

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PULMONARY REHABILITATION is defined as “an evidence-based, multidisciplinary and comprehensive intervention for patients with chronic respiratory disease who are symptomatic and often have decreased daily life activities.”^{1(p1391)} Current national and international guidelines state that exercise and education should be included in pulmonary rehabilitation programs. There are evidence-based recommendations for the exercise component, including the intensity, frequency, and type of exercise necessary, but there is limited research with which to direct the content and delivery of the education component.¹⁻³ Development of such a component has been highlighted as an important area for research.⁴

It is not known which topics are essential in the educational component of pulmonary rehabilitation. Current guidelines provide a range of topics, but it is unclear whether patients' perspectives were incorporated in their development. Several documents^{1,5-8} highlight the importance of the patient's perspective in optimizing health care.^{1,5-9} For example, the expert patient document states that the “era of the patient as a passive recipient of care is changing and being replaced by a new emphasis on the relationship between the NHS [National Health Service] and the people it serves—one in which health professionals and patients are genuine partners seeking together the best solutions to each patient's problem, one in which patients are empowered with information and contribute ideas to help in their treatment and care.”^{7(p9)} Other recent documents specifically support the partnership approach to the management of respiratory disease.⁸

Our purpose in this study was to ascertain from patients' perspectives what should be included in the educational component of pulmonary rehabilitation and how those components should be delivered, and to compare patients' perspectives with the views of health professionals.

METHODS

Participants

We invited a purposive sample of 49 patients from the Regional Respiratory Centre at Belfast Trust City Hospital (Ireland) to participate in this study; 32 patients attended the resulting focus group meetings. All patients had a diagnosis of chronic obstructive pulmonary disease (COPD) classified by the National Institute of Clinical Excellence (United Kingdom) guidelines.⁴ Six focus groups were conducted (members of 2 groups had previously attended pulmonary rehabilitation, those in 2 other groups had not, and 2 groups were a mixture of people who had and had not had pulmonary rehabilitation). A purposive sample of health professionals knowledgeable about COPD and pulmonary rehabil-

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Table 1: Patient Focus Group Characteristics

Categories	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6	Total
Patients attending	8	7	5	5	4	3	32
Male/female	6/2	5/2	4/1	4/1	3/1	3/0	25/7
Group	PR	PR	Non-PR	Mixed	Mixed	Non-PR	NA
Mean age \pm SD (y)	68.1 \pm 6.8	65.6 \pm 7.7	67.4 \pm 11.2	71.8 \pm 10.8	60.5 \pm 2.4	68.7 \pm 4.2	67.1 \pm 8.1
FEV ₁ \pm SD (%)	36.5 \pm 4.2	46.9 \pm 11.8	52.4 \pm 1.1	44.2 \pm 1.9	19.5 \pm 5.2	47.0 \pm 4.6	41.3 \pm 11.6
Lung function category ⁴							
Mild	0	2	5	0	0	1	8
Moderate	8	5	0	5	0	2	20
Severe	0	0	0	0	4	0	4
LTOT (n)	2	2	0	1	1	1	7
Smoking status							
Smoker	1	3	0	1	2	0	7
Ex-smoker	7	4	5	3	2	3	24
Nonsmoker	0	0	0	1	0	0	1
Living alone	1	1	0	3	0	1	6
Employment							
Retired	7	4	4	4	2	2	23
Disability	0	2	1	1	2	1	7
Working	1	1	0	0	0	0	2

Abbreviations: FEV₁, forced expiratory volume in 1 second; LTOT, long-term oxygen therapy; NA, not applicable; PR, pulmonary rehabilitation; SD, standard deviation

itation, and who were unaware of the results from the patient focus groups, were invited to participate in a multidisciplinary focus group. The health professional focus group (n=8) included a consultant respiratory physician, a general practitioner, a respiratory nurse specialist, 2 respiratory physiotherapists, a dietician, an occupational therapist, and a representative from the citizen's advice bureau. They were employed in different primary and secondary care centers in Northern Ireland, and all had experience in pulmonary rehabilitation and the management of patients with COPD. Another nurse specialist, a social worker, and a clinical psychologist were unable to attend the focus group.

Procedure

To guide the focus groups we developed a series of key open-ended questions and topics relating to educational needs and delivery preferences (available on request from the corresponding author). An experienced moderator facilitated each focus group and an assistant moderator recorded the discussions of all groups. All focus group sessions were videotaped. The Office for Research Ethics Committee in Northern Ireland approved the study. Participant confidentiality was ensured and written informed consent was obtained before each group met.

Analysis

Data were analyzed using a grounded theory approach.¹⁰ Analyses of the focus groups were conducted in 4 stages: debriefing, transcription, selective coding, and triangulation. Debriefing about the process was held after each group meeting and the topics discussed were reviewed and compared with those of the previous focus group. The schedule of topics for discussion by the subsequent focus group was modified if appropriate. Transcription involved manually recording the information from each focus group. Selective coding involved grouping themes together as categories and subcategories to facilitate the identification of key topics, and identification

information on the method of delivery of these topics. A summary of the main topics identified was posted to all participants in every focus group to verify the results. Saturation (no new themes emerging from additional focus groups) was achieved by focus group 5. Triangulation involved verification of categories and subcategories by a second researcher.

RESULTS

Thirty-two patients attended meetings of 6 focus groups; table 1 describes their characteristics. Eight health professionals attended 1 focus group meeting. From the groups' discussions, 6 key topics relating to the content of an educational component of pulmonary rehabilitation were identified (table 2).

Disease Education

A lack of knowledge about COPD was consistent across all the patient focus groups; patients were generally dissatisfied with the amount of information they were given when diagnosed as having COPD and during their continuing care. They were unclear about the etiology of COPD. Many acknowledged that their disease was related to cigarette smoking, but they also believed that occupational or environmental factors contributed to their having the disease.

The results suggest that patients and health professionals were ambivalent about the amount of information given about the trajectory and progression of COPD. The patients wanted information, but some felt that discussing issues such as living wills and end-of-life was inappropriate in a group setting.

The health professionals also believed patients with COPD have a poor understanding of the disease and agreed that information about the disease and its progression should be given to patients during their rehabilitation. There was a consensus that information about end-of-life issues should be given on an individual basis and that a group format was inappropriate for that topic.

Table 2: Key Education Topics and Suggested Content for Pulmonary Rehabilitation

Key Education Topics	Suggested Content
Disease education "When you are first diagnosed they say 'Oh yes, you've got COPD,' but that's the end of it, nobody tells you or explains anything to you" -PR group, male, moderate disease	Anatomy and pathophysiology of COPD, causes, disease progression
Management of breathlessness and the physical impact of COPD ". . . I can't walk from the living room to the toilet when I am having a bad day." -PR group, female, moderate disease	Practical strategies for ADLs, walking, pacing, panic reduction, energy conservation, positions of ease, benefits of exercise, work simplification
Management of an exacerbation. "I'm inclined to hold on and say, 'No. This is a cold and I'm going to get better.'" -PR group, female, severe disease (LTOT)	Recognition of worsening symptoms, when and where to seek help, feedback about management decisions
Medication "Nobody tells you how to take it [inhaler] or when to take it."-PR group, male, moderate disease (LTOT)	How, when, and why to use medications. Potential medication interactions, contraindications, and regime feasibility. Cross-infection and equipment maintenance
Psychosocial support "Depression is the biggest problem. It is the worst, because if you were an active person all your life and now you're inactive, it's hard to accept." -Non-PR group, male, mild disease	Management of psychosocial symptoms, including management of depression, panic, anger, and frustration. Information about, and benefit of, support groups. Making lifestyle adjustments (eg, role reversal)
Welfare and benefits system "I am horrified to hear that people are not getting their allowances. . . . There are so many things out there to help us but many of us don't know about them." -PR group, female, severe disease (LTOT)	Information on and benefit of support groups. Welfare and benefits system disability entitlements, access to home aids and appliances

Management of Breathlessness and the Physical Impact of COPD

Breathlessness was consistently described as the most distressing symptom of COPD. Patients described the extensive impact of breathlessness on their ability to perform activities of daily living (ADLs). Patients described techniques and adjustments that they found useful in managing their breathlessness; these included permanently discontinuing some activities (eg, walking, housework, socializing).

Patients who had attended a pulmonary rehabilitation program felt that exercise relieved their breathlessness and improved their ability to perform ADLs. Patients who had not had pulmonary rehabilitation were generally unaware that exercise could improve their symptoms. Only a few patients reported continuing their exercise regime after they completed rehabilitation, but indicated that if they had understood the purpose of the exercises, they would have been more inclined to continue them.

There was consensus among the health professionals that breathlessness is a major concern for COPD patients. They believed that if the patients understood their disease and its associated breathlessness, they would be less frightened and would be more likely to increase their physical activity. They also felt that ways to manage breathlessness—including pacing, positions of ease, and work simplification—should be

incorporated into the education component of pulmonary rehabilitation.

Management of an Exacerbation

Patients could not clearly explain how they would recognize an exacerbation of their illness and had inconsistent views about which symptoms are exacerbation indicators and when to seek medical attention. Patients felt that after an exacerbation, it would be useful to receive feedback that would help them manage future exacerbations more appropriately.

The health professionals acknowledged that many patients with COPD cannot recognize the signs and symptoms of an exacerbation, and agreed that pulmonary rehabilitation is an appropriate forum for teaching patients, their families, and significant others about exacerbations. They felt that a written self-management plan would be useful in helping patients know what to do in an emergency, thus reducing inappropriate hospital admissions.

Medication

Patients were uncertain as to when and how they should take their medications. Despite their complaining about inadequate information, they often fail to ask for assistance. Patients with comorbidities described concerns about potential drug interactions.

Health professionals recognized that patients do not understand their medications and agreed that information about medications, equipment maintenance, and cross-infection, should be included in the education component of pulmonary rehabilitation.

Psychosocial Impact of COPD

Patients asserted that COPD had had a considerable psychosocial impact on their lives. They consistently reported experiencing depression and frustration associated with their chronic illness, and they also described panic, anger, social isolation, and a loss in confidence that had affected their ADLs.

Patients appeared to have previously had stereotypically gender roles within their households and found it difficult to adjust to role reversal because of COPD. Female patients reported having difficulty doing housework and described how their partners had to learn how to cook; similarly, male patients described difficulties with gardening, household maintenance, and washing their cars.

Patients were largely unaware of the existence of support groups, but many felt that such support would be useful in sharing experiences with, and knowledge of, COPD.

The health professional focus group reported that the psychosocial impact of COPD was as important as the physical impact. They felt that pulmonary rehabilitation would help patients who feel guilty about their history of cigarette smoking, or who have low self-esteem, depression, boredom, and panic and/or anxiety attacks. The lack of access to a clinical psychologist was a barrier to providing expert psychosocial support for patients. Additionally, the health professionals agreed that information about intimate relationships is important but that the topic is not suitable for group discussion.

Welfare and Benefits System

Patients found it difficult to acquire information about the welfare and benefits system in Northern Ireland. They agreed that more information about financial, social, and housing benefits would be useful, as would access to, and assistance from, someone who could explain the benefits system. Some patients knew how to request home aids and appliances but others were unaware of the procedure.

The health professionals agreed that information about the welfare and benefits system was important in pulmonary rehabilitation, but said that it is often difficult to gain access to an appropriate person who could provide that information. They were, for example, concerned about recommending household aids for patients where the provision of services is fragmented, or in areas that have long waiting lists for occupational therapy.

Table 3 lists the 6 key considerations for the format and delivery of pulmonary rehabilitation that were also identified after analysis of the groups' discussions.

Format for Delivery

All patients, whether they had attended a pulmonary rehabilitation program or not, recommended group sessions consisting of practical demonstrations of treatment strategies, including the use of visual aids and models. Patients who had attended pulmonary rehabilitation reported that they were too tired to learn after the exercise component and indicated that the education session should be held first. All patients felt that peer support and shared knowledge were important aspects of learning to live with COPD.

The health professionals also preferred a group format because shared knowledge and peer support are important components of pulmonary rehabilitation.

Educator

Patients agreed that selection of a competent educator was very important to a group's dynamics. They did not want to dictate which health professionals should be involved, but were consistent in their view that the educator should be enthusiastic and knowledgeable and have good communication skills, including the ability to talk to them in "plain" language.

The health professionals discussed the difficulty of recruiting educators who have the appropriate mix of skills. When a particular health professional is not available, his/her topic is omitted—for example, the psychosocial needs of patients were often not fully addressed because there was limited access to a clinical psychologist.

Location

Patients had different views on the most appropriate location for pulmonary rehabilitation. Those who had been in pulmonary rehabilitation felt it should be hospital based, whereas those without such experience did not have a strong opinion but felt that it should be local and accessible. Factors considered to be important included parking availability, wheelchair access, and the distance patients might have to walk outside.

The health professionals agreed that pulmonary rehabilitation should take place in a location convenient for patients.

Duration and Frequency

Patients were unable to prove a clear guide concerning the optimal duration of a program, with their suggestions ranging from twice weekly to monthly. The general view was that they would attend for as long as they perceived a program to be beneficial. They also wanted flexibility in the number of sessions they could attend, as well as a greater choice of days and times.

There was no recommendation from health professionals concerning the optimal duration of the program, but the merits of a fixed or rolling program were discussed.

Supplementary Information

Patients felt that the education sessions should be supplemented with a packet of comprehensive information on topics not covered in the group sessions and/or that might be useful at a later stage of the disease, such as living wills, sexual relationships and intimacy, oxygen therapy, and airway clearance. Suggested formats included leaflets with clearly marked sections for easy reference, videotapes, and DVDs.

Health professionals agreed that leaflets, videos, and DVDs would be a useful complement to the program.

Long-Term Support

The patients who had attended pulmonary rehabilitation reported having enjoyed the program and felt that it was beneficial. They voiced a need for follow-up activities with a knowledgeable leader, similar to the process for pulmonary rehabilitation.

The health professionals expressed concern for the patients' emotional well being once they had completed a pulmonary rehabilitation program. The potential benefits of follow-up, community-based support were discussed, but the group acknowledged that the intensive support patients with COPD preferred would be unattainable with the available resources.

DISCUSSION

This qualitative study has identified from patients' perspectives what should be included in the educational component of pulmonary rehabilitation, and how it should be delivered. Pa-

Table 3: Key Factors for the Format and Delivery of the Educational Component of Pulmonary Rehabilitation

Suggested Format	Suggested Delivery
<p>Format and method of delivery</p> <p>"If other people have the same thing, I would like to know how they cope with it; it might help me."</p> <p>-PR group, male, moderate disease</p>	<p>Group format with peer support, practical demonstrations, visual aids and models, consider education prior to exercise session. Offer a range of formats, eg, video, DVD, leaflet, website.</p>
<p>Educator and delivery method</p> <p>"I think the doctors would be talking in talk we wouldn't understand, using these words that would mean nothing to us."</p> <p>-Mixed group, female, severe disease (LTOT)</p>	<p>Credible and knowledgeable individual, layman's language.</p>
<p>Location</p> <p>"I think it [pulmonary rehabilitation] should be hospital-based because I think you are coming into an environment that is very health conscious, you know, it is for our benefit. If you went to a town hall or the gym you wouldn't have the same confidence."</p> <p>-PR group, female, moderate disease (LTOT)</p>	<p>Convenient, accessible, local, access for disabled, adequate parking for cars.</p>
<p>Duration and frequency</p> <p>"It would take you to get the first one over [first education session] and then you would say that's been good, I could do with another few [education] sessions."</p> <p>-Mixed group, male, severe disease</p>	<p>Weekly or monthly, must be flexible.</p>
<p>Supplementary information</p> <p>"You should have a leaflet made for the disease with diagrams on the side. If you are short of breath, what to do. Then as the stages go on and you know you are going to get worse in later years. You know the symptoms that you are looking for."</p> <p>-PR group, female, moderate disease</p>	<p>Provide supplemental information to support delivery of the educational topics during PR. Provide additional information on topics not covered (eg, end of life/living wills, airway clearance, sexual relationships and intimacy, oxygen therapy, and others).</p>
<p>Long-term support</p> <p>"I think if you went to the exercises outside the clinic with people who haven't got what you got, I think it would make me feel I'm ill."</p> <p>-PR group, female, moderate disease</p>	<p>Arrange follow-up and provide appropriate opportunities for ongoing exercise and social support</p>

tients identified 6 key topics that should be supplemented by written and/or audiovisual materials. Patients would like group information sessions featuring knowledgeable individuals, regardless of their professional background, who speak in layman's language. They also want information about opportunities for ongoing exercise and patient support groups.

Guidelines and position statements outline a range of topics that could be included in the educational component of pulmonary rehabilitation, but it is often difficult to include all these topics within the designated resources of, for example, a 6-week program. Partnership with patients is important and these guidelines and position statements do not indicate whether all the suggested topics are essential and/or have been developed in partnership with patients.^{1,2,5-9} Similarly, studies

that have evaluated the efficacy of education in pulmonary rehabilitation have not stated whether the content of the educational intervention was developed in partnership with patients.^{11,12} This is the first study to provide information from the patients' perspectives about essential topics that should be included in the educational component of pulmonary rehabilitation.

There is some debate as to whether patients can make informed decisions about their education needs, or whether health professionals with expertise in the management of respiratory conditions always know best. It is likely that the perspectives of both the patients and the health professionals are important, and therefore should be combined in developing an educational component of pulmonary rehabilitation.^{4-7,9} The

key topics identified in this study is based on what the patients as well as the health professionals deemed to be important. Furthermore, the topics and the suggested delivery formats were consistent in all groups.

It is also important to consider the efficacy of the therapies relating to each topic; where evidence is lacking, it is proposed that there is some physiologic rationale to justify their inclusion.¹²⁻¹⁶ There is also some evidence that education about their respiratory condition can change patients' behavior in managing the condition.^{14,17}

Study Limitations

Topics such as end-of-life issues and sexual relationships and intimacy were considered inappropriate for discussion within a group setting by both patients and health professionals. Further research is required to help health professionals identify when and how these issues should be discussed with patients.¹⁶ Other topics such as oxygen therapy, smoking, airway clearance, and nutrition should be included in supplementary material and, in our opinion, could be included in a group session. Some patients may have difficulty coping with sex-specific role loss associated with increasing disability and sex-specific coping strategies may need to be considered.¹⁸

There has been an expansion of community-based pulmonary rehabilitation programs that may have less diverse multidisciplinary teams available to deliver specific educational topics. Where the correct skill mix of team members is not available, the educational sessions could be supplemented by a pulmonary rehabilitation tool kit or education package.^{19,20}

The views generated by focus groups are qualitative and may have limited generalizability. We recruited patients across the disease spectrum and from a wide geographical area. There were small numbers of participants in some of the patient focus groups, but in all the groups the patients expressed their views frankly and provided valuable insights into living with COPD and their educational needs. Although the health professional focus group was conducted without knowledge of the patients' views, the opinions relating to the key topics and format for delivery were similar. We achieved saturation within the patient and health professional focus groups.

CONCLUSIONS

This study has identified deficits in patients' knowledge, understanding, and management of COPD. It provides evidence on the key topics, content, and format for delivery of the educational component for pulmonary rehabilitation. Future research should focus on the development and assessment of the efficacy of an educational package or tool kit that would facilitate equitable patient access to education in pulmonary rehabilitation.

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