

# Improving the uptake of pulmonary rehabilitation in patients with COPD: qualitative study of experiences and attitudes

David Harris, Mark Hayter and Steven Allender

## ABSTRACT

### Background

Pulmonary rehabilitation can improve the quality of life and ability to function of patients with chronic obstructive pulmonary disease (COPD). It may also reduce hospital admission and inpatient stay with exacerbations of COPD. Some patients who are eligible for pulmonary rehabilitation may not accept an offer of it, thereby missing an opportunity to improve their health status.

### Aim

To identify a strategy for improving the uptake of pulmonary rehabilitation.

### Design of study

Qualitative interviews with patients.

### Setting

Patients with COPD were recruited from a suburban general practice in north-east Derbyshire, UK.

### Method

In-depth interviews were conducted on a purposive sample of 16 patients with COPD to assess their concerns about accepting an offer of pulmonary rehabilitation. Interviews were analysed using grounded theory.

### Results

Fear of breathlessness and exercise, and the effect of pulmonary rehabilitation on coexisting medical problems were the most common concerns patients had about taking part in the rehabilitation. The possibility of reducing the sensation of breathlessness and regaining the ability to do things, such as play with their grandchildren, were motivators to participating.

### Conclusion

A model is proposed where patients who feel a loss of control as their disease advances may find that pulmonary rehabilitation offers them the opportunity to regain control. Acknowledging patients' fears and framing pulmonary rehabilitation as a way of 'regaining control' may improve patient uptake.

### Keywords

chronic obstructive pulmonary disease; communication barriers; patient acceptance of healthcare; qualitative research.

## INTRODUCTION

Pulmonary rehabilitation uses multidisciplinary teams to optimise the physical and social functioning of patients with chronic obstructive pulmonary disease (COPD). It may reduce inpatient stay and hospital admission with exacerbations of COPD<sup>1</sup> and has been supported by a Cochrane review,<sup>2</sup> National Institute for Health and Clinical Excellence (NICE) recommendations,<sup>3</sup> and the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines.<sup>4</sup>

Patients may be reluctant to accept the opportunity to undertake rehabilitation; this has been confirmed by the local pulmonary rehabilitation service. Uptake figures of between 33% and 39% of those with COPD have been reported from outpatient clinics.<sup>5-7</sup> A number of factors affect the adherence to pulmonary rehabilitation,<sup>8,9</sup> depression, a significant risk factor for dropout,<sup>5</sup> has been reported in 20-60% of patients with COPD.<sup>10</sup>

Although there is an understanding about predictors of success in secondary care, this study reflects attitudes in a primary care population. A population that was naive regarding pulmonary rehabilitation was interviewed, with the aim of understanding their concerns around accepting an offer of it. By framing the offer of pulmonary rehabilitation with patients' concerns in mind, it may be possible to improve its uptake and completion.

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## How this fits in

Pulmonary rehabilitation results in improvements in general and disease-specific health status, and may reduce hospital admission and inpatient stay with exacerbations of COPD. GPs are being encouraged to look at ways of improving chronic disease management and reducing hospital admissions. By understanding the barriers that patients with COPD face when it comes to accepting an offer of, and participating in, pulmonary rehabilitation, it may be possible to improve its uptake.

### METHOD

Patients were recruited from a suburban general practice in north-east Derbyshire, UK — a former coal-mining area. The practice has an asthma and COPD service delivered by practice nurses, one of whom has a diploma in asthma management. Few patients have undertaken pulmonary rehabilitation.

A purposive sample of patients with COPD, confirmed by spirometry, was identified using a computer-aided search of medical records. Patients were excluded if they had a terminal diagnosis, dementia, severe osteoarthritis, peripheral vascular disease, uncontrolled angina, or left-ventricular failure. Interviews were undertaken at each patient's home between January and April 2007; participants had an opportunity to ask questions before signing consent for the study. A smoking and employment history were taken. The Medical Research Council<sup>11</sup> (MRC) dyspnoea scale was used to assess symptoms and a Hospital Anxiety and Depression Score<sup>12</sup> (HADS) was completed.

#### Data collection

The interview undertaken by a researcher used the topic list in Box 1. The researcher encouraged the participant to clarify or reflect upon what was reported. Responder validation was undertaken with two patients, who reviewed the coding of their interviews and the model (Figure 1) proposed to explain the findings.

### Box 1. Topics covered in the participant interview.

- How does COPD affect you?
- What do you do to try to help?

Patients were shown an information sheet about pulmonary rehabilitation and what was involved.

- How do you feel about pulmonary rehabilitation?
- What might prevent you from attending pulmonary rehabilitation?
- How could we make it easier?
- Are there any other issues you would like to raise?

### Analysis

Open inductive coding through line-by-line reading of the transcripts of patient interviews was undertaken using the principles of grounded theory.<sup>13,14</sup> Data collection and the initial stages of analysis took place simultaneously and continued until data saturation had occurred, that is, new data did not add to the developing theory.<sup>13,14</sup> Two coders checked a sample of transcripts for intercoder verification. All participants were given the opportunity to convey their own meanings and interpretations through the explanations that they provided.

Primary codes were derived by reading patients' statements and deciding which key message or concept was being reported in each. Core categories were subsequently identified that attempted to explain behaviours; these were then used to develop a theory to explain the behaviour. Data from each interview were tabulated to look for deviant cases. This enabled the codes mentioned by different participants to be looked at to see if patterns or associations were emerging and to detect associations between codes for individual participants, for example, breathlessness and slowing down.

### RESULTS

One hundred and ten patients were contacted, of whom 78 declined to be interviewed and 16 did not reply. Sixteen (12 men and four women) consented to interview. Patients' characteristics are summarised in Table 1. The average age of the participants was 66.8 years and two of the responders were smokers. Disease severity was assessed using spirometry readings from patients' records (in accordance with NICE guidelines).<sup>15</sup> Reported breathlessness scales for participants were the following MRC1,  $n = 1$ ; MRC2,  $n = 5$ ; MRC3,  $n = 3$ ; MRC4,  $n = 5$ ; MRC5,  $n = 2$ . HADS scores were the following: normal,  $n = 7$ ; mild anxiety,  $n = 5$ ; mild anxiety and depression,  $n = 1$ ; moderate anxiety and depression,  $n = 2$ ; moderate anxiety and severe depression,  $n = 1$ . Patients who declined to take part or did not reply were more likely to be women, have mild disease, and smoke, compared with those who agreed to participate.

One participant had received pulmonary rehabilitation as an inpatient; no other participant had been offered pulmonary rehabilitation. The NICE guidelines for COPD state that pulmonary rehabilitation is appropriate for patients who consider themselves to be functionally disabled by COPD (this usually equates to a score on the Medical Research Council [MRC] dyspnoea scale of three or above). Some patients whose MRC dyspnoea score was below three were included, as pulmonary rehabilitation can help patients improve their exercise performance, symptoms, and quality of life.<sup>16,17</sup>

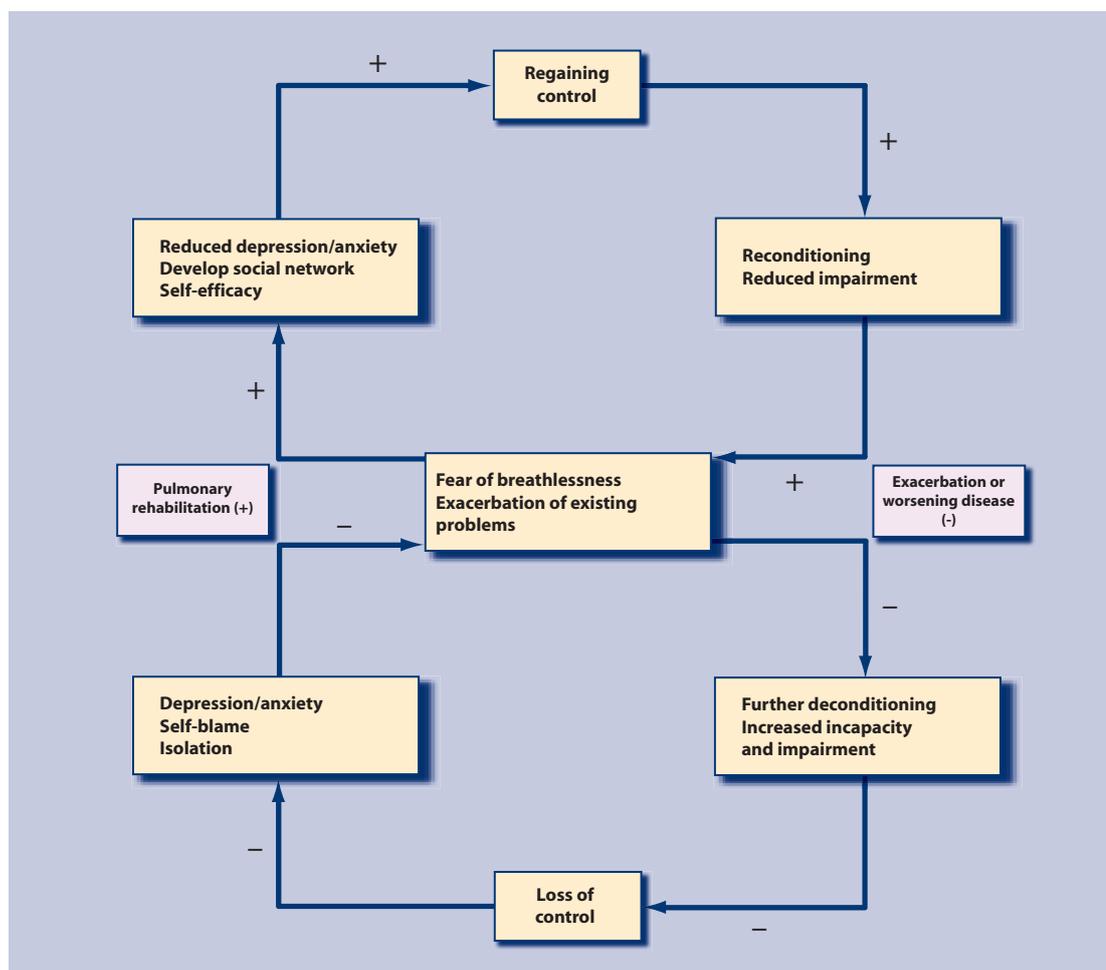


Figure 1. A model to illustrate the proposed effect of pulmonary rehabilitation in helping patients regain control.

The results are presented under the main thematic headings identified in the analysis.

### Losing control

Participants' remarks highlighted some aspects of losing control: breathlessness, limiting activity, losing the ability to do certain things, self blame, therapeutic nihilism, stoicism, lack of information about diagnosis, and patients' versus health professionals' agenda.

Breathlessness was a key factor described by all participants, irrespective of disease severity:

*"I'm beginning to lose my breath just talking ... you can't rush about all doomed out, you just sit down and get your breath in your own time."* ('B', Male, 72 years, severe COPD, MRC5 mild anxiety and depression)

*"If I try to rush I'm out of breath ... I think, "oh I can't get my breath" ... if I talk a lot sometimes I get out of breath."* ('L', female, 73 years, mild COPD, MRC4, HADS normal)

Limiting activity reflected the impact that

breathlessness had on activities of daily living and resulted in behaviours like slowing down or losing the ability to do certain things, such as domestic tasks or leisure pursuits:

*"I've had to learn to adapt and move a lot slower than what I used to do ... I've learnt to walk slower and take things steady ... I've been like it a few years now."* ('C', male, 58 years, moderate COPD, MRC4, HADS normal)

*"Decorating and all that sort of thing, mostly the wife has to do that now because I can't keep getting up on ladders ... or we have somebody in to decorate ... I can't do them anymore with this breathing job."* ('F', male, 63 years, severe COPD, MRC2, HADS normal)

*"I can no longer carry my [fishing] tackle and walk to a peg on the bank. My wife has to come with me ... and carry the stuff because I just can't carry it."* ('D', male, 64 years, mild COPD, MRC4, HADS normal)

A number of patients admitted that smoking had

**Table 1. Patient characteristics.**

Category	Agreed to interview	Declined interview	No reply
Participants	16	78	16
Male	12	38	7
Female	4	40	9
Smokers	2	26	9
Ex-smokers	14	52	7
Average age, years (SD)	66.8 (6.9)	71.0 (8.6)	72.0 (9.7)
Mild disease (FEV1 80–50%)	9	59	13
Moderate disease (FEV1 49–30%)	5	17	3
Severe disease (FEV1 <30%)	2	1	0

FEV1 = forced expiratory volume in the first second.

contributed to their COPD and that they were responsible for their condition:

*'I do know that smoking is the cause of it ... it worries me that I've got it through my own fault.'* ('K', Male, 60 years, moderate COPD, MRC4, mild anxiety)

*'... what with working in a dusty environment ... and combined with smoking, that's what caused it.'* ('F', male, 63 years, severe COPD, MRC2, normal HADS)

Some participants made statements that encompassed broader aspects of loss such as deconditioning, loss of independence, and loss of self-esteem:

*'It's a vicious circle, you can't exercise if you can't ... you get out of breath ... it seems that it's an ever-decreasing circle.'* ('F', male, 63 years, severe COPD, MRC2, HADS normal)

*'Walking a little bit more slowly ... it's a bit degrading ... its awful ... but I've got to learn to do it.'* ('N', female, 57 years, mild COPD, MRC2, moderate anxiety and depression)

Some patients felt that they had not received the information they required about the diagnosis or management of their condition:

*'... as I say I wasn't even sure, it had never been put to me, formally put to me that I'd got this obstructive pulmonary or whatever they call it.'* ('D', male, 64 years, mild COPD, MRC4, HADS normal)

*'I would have preferred to have a clear explanation about my breathing problem.'* ('O', male, 65 years, moderate COPD, MRC1, HADS normal)

Others felt that nothing could be done for them. In some cases, this nihilism represented a lack of faith in health professionals and, possibly, expressed frustration. When problems arose, this seemed to reflect a breakdown in communication between patient and practitioner, resulting in a dysfunctional consultation:

*'... she said, "you wants some new lungs, and they'll not give it to you". So I said, "well that's it then, I'll just carry on, on my bloody own".'* ('B', male, 72 years, severe COPD, MRC5, mild anxiety and depression)

*'Well if I'm truthful I don't think they believed what I was saying, you get the feeling that nobody is interested.'* ('J', female, 72 years, mild COPD, MRC4, moderate anxiety and depression)

Some participants also felt that they were being rushed and following a health professional's agenda rather than their own. One 63-year-old male participant with severe COPD ('F', MRC2, HADS normal) wanted to, *'... do things in my own time ...'*

### Regaining control

Patients frequently reported how they regained control of their lives, and this included management of their COPD. This included using medication, changing behaviours, normalising their symptoms, developing self-efficacy, adapting, and becoming more stoical.

Several patients used medication to regain control of their symptoms; an example of the benefit of self-management was also reported:

*'... if it's been a bad day and I think I can't breathe I'll come down and use my nebuliser and I'm alright ... I don't use it a lot, I don't want to get addicted to it, but it's helpful.'* ('J', female, 72 years, mild COPD, MRC4, moderate anxiety and depression)

*'I don't think I'd be in control if it wasn't for the medication, I do rely on them, I wish I didn't but I have to.'* ('F', male, 63 years, severe COPD, MRC2, HADS normal)

*'I've got a supply of antibiotics and steroids. It's happened several times at the weekend when the surgery is closed that I've needed them, it has been a very good thing.'* ('C', male, 58 years, moderate COPD, MRC4, HADS normal)

A number of patients reported behaviour changes

that had resulted in health benefits. Some normalised their symptoms as a coping strategy, while others misattributed their symptoms to 'getting older' rather than COPD:

*'I'm trying to get this weight off, walking in the park ... I'm trying to help myself. I've built it up now and I stride out, I love it.'* ('E', male, 72 years, mild COPD, MRC3, moderate anxiety and depression)

*'... getting breathless has become normal for me, I don't even notice it.'* ('D', male, 64 years, mild COPD, MRC4, HADS normal)

*'... you know like, oh dear, slowing down ... so to console my own mind I've thought, "well you are getting older". So I don't worry.'* ('N', female, 57 years, mild COPD, MRC2, moderate anxiety and depression)

Some patients took the initiative and reported what they did to help with their condition, such as exercise or training, or breathing control:

*'... that's an exerciser there, yes, it's easier on my legs and my joints [than walking] ... and I can quite enjoy it.'* ('P', male, 69 years, mild COPD, MRC3, mild anxiety)

*'I do like, you know, try and control my breathing a bit as I, as I come up the street, you know to get into a rhythm like.'* ('M', male, 58 years, mild COPD, MRC2, mild anxiety)

Many patients reported on changes they had made, such as delegation and limiting their activity, as well as stoicism that enabled them to reconcile some of their losses:

*'I mean, there's some things I could do, like DIY, but I can't do them because of my health, so I have to pay somebody to do them.'* ('F', male, 63 years, severe COPD, MRC2, HADS normal)

*'I just don't push myself anymore, I used to but not now, no ... [when] people come ... I hope they come to see me, not to look at my mess and at my walls where you know there's dust on things and so, I don't bother now, not so much.'* ('L', female, 73 years, mild COPD, MRC4, HADS normal)

*'I don't complain, I never have done.'* ('A', male, 78 years, mild COPD, MRC5, HADS normal)

During the analysis primary codes were tabulated,

revealing associations between the codes. Patients who made statements associated with self-efficacy, for example undertaking self-directed exercise or training, adopting healthy lifestyles, and in particular having stopped smoking, were more likely to mention potential benefits of team working and pulmonary rehabilitation.

### **Pulmonary rehabilitation**

After establishing the effect that COPD had on patients' lives and the changes they had made, the barriers and facilitators to accepting an offer of pulmonary rehabilitation and undertaking it were examined. A number of key factors were reported. Motivators, such as being able to play with grandchildren, was a reason to improve symptoms. The opportunity to take part in the rehabilitation was also a motivator for others.

*'I take the grandkids to the park. I've played with them, not running but walking. After so long I say, "I can't do no more, I'm going to have to sit down". They're only young, they don't understand.'* ('F', male, 63 years, severe COPD, MRC2, HADS normal)

*'... I don't know whether it would be for me ... but if it's [pulmonary rehabilitation] going to help my breathing, yes, I will do it.'* ('B', male, 72 years, severe COPD, MRC5, mild anxiety and depression)

Two patients were keen to participate in rehabilitation, with the proviso that they would need to check with their GP that it would be appropriate:

*'Well if I were told that they [GPs] thought it [pulmonary rehabilitation] could improve me ... anything that could make me better, I'm willing to take part.'* ('P' male 69 years, mild COPD, MRC3, mild anxiety)

*'I'd want my own doctor to say it was okay for me, I usually ask them, because they're up-to-date with things that are going off.'* ('K', Male, 60 years, moderate COPD, MRC4, mild anxiety)

The location and timing of the programme, as well as anxiety regarding getting to an unfamiliar place, were reported:

*'... the only concern as I said earlier on, is getting to the place wherever it's going to be, because I'm not familiar with them parts.'* ('F', male, 63 years, severe COPD, MRC2, HADS normal)

*'... I'd say afternoon really [would be the ideal time for the programme to take place] ... when I've been on my nebulizer I'm not so bad.'* ('N', female, 57 years, mild COPD, MRC2, moderate anxiety and depression)

*'If it's too early in the morning, we've got a 92-year-old mother-in-law that we have to see every day.'* ('O', male, 65 years, moderate COPD, MRC1, HADS normal)

Surprisingly, the majority of patients felt transport was not a problem:

*'... I can drive ... I've got a car and I've got a family to run me about anyway.'* ('C', male, 58 years, moderate COPD, MRC4, HADS normal)

Pulmonary rehabilitation involves group work, which was ideal to discover patients' views. The value of sharing experiences, support of others, and social aspects were benefits to some, but others were not so keen:

*'... if you're doing it in a group that would help I suppose because you've got other people who've got the same or worse, or better problems ... Talking to other people would be useful I suppose.'* ('D', male, 64 years, mild COPD, MRC4, HADS normal)

*'I've never been one for group activities ... it seems too Americanised to me.'* ('C', male, 58 years, moderate COPD, MRC4, HADS normal)

A feature of pulmonary rehabilitation is a regular, tailored exercise session; this was a concern to many patients:

*'... exercise and walking ... Well I'd be more breathless than ever ... I might make myself ill, but I'd have a go ...'* ('N', female, 57 years, mild COPD, MRC2, moderate anxiety and depression)

*'... if it's ... the exercise is too strenuous my back ... er, lower back pain wouldn't take it.'* ('F', male, 63 years, severe COPD, MRC2, HADS normal)

Irrespective of their own illness, many patients had other responsibilities such as the provision of childcare, working, or caring for an older relative:

*'Well I look after my grandson sort of*

*permanently ... he's quite a handful.'* ('G', female, 68 years, moderate COPD, MRC3, mild anxiety)

*'... the biggest problem I would probably have is the sessions in the week with my job.'* ('K', male, 60 years, moderate COPD, MRC4, mild anxiety)

## DISCUSSION

### Summary of the main findings

Successful management of COPD incorporates a number of components, one of which is pulmonary rehabilitation. The purpose of this study was to understand which factors acted as barriers or facilitators to the acceptance of the offer of pulmonary rehabilitation by patients with COPD.

The impact of COPD on patients' lives has been previously reported<sup>18,19</sup> and is echoed by this study's participants. This information was included as it helps us understand why patients might be unwilling to accept rehabilitation. When examining associations between factors reported by participants it was found that those who scored more highly for anxiety and depression were more likely to report losses, breathlessness, and fear exercise (loss of control), irrespective of the severity of their disease or their MRC breathlessness scores. Increased disease severity and higher MRC breathlessness score did not seem to be linked to a larger HADS, although numbers of participants were small in this study.

Some participants were positive about the benefits that pulmonary rehabilitation might offer, despite having concerns about exercise and having 'slowed down'. These participants tended to have positive views about the benefits of exercise and many were undertaking some form of exercise already (regaining control). A subset of patients who were concerned about exercise mentioned the potential impact of it on their coexisting medical problems; in two cases the patients wanted their GP's verification that pulmonary rehabilitation would be safe for them.

Some participants mentioned motivators for undertaking pulmonary rehabilitation, such as playing with grandchildren. Despite all these participants mentioning concerns about breathlessness and exercise in association with pulmonary rehabilitation, they all wanted to improve their symptoms. All reported losses, for example, of their ability to do previous tasks, and a number mentioned that they were to blame for their condition as they had smoked. There was an association with self-efficacy, such as having stopped smoking and the perceived benefits of team-working. None of the participants who were motivated to undertake pulmonary rehabilitation, or showed evidence of self-

efficacy had mentioned any codes associated with nihilistic views, stoicism, nor attributed their symptoms to coexisting medical problems.

### **Strengths and limitations of the study**

Sixteen participants were interviewed, which is similar to the number of participants in other qualitative studies<sup>2,18,19</sup> but, as only two participants were current smokers and only four were women, these groups were underrepresented. With regard to smoking, this may be important, as the habit is strongly associated with non-adherence with exercise programmes.<sup>6</sup>

All degrees of disease severity were represented, but patients were selected from one GP practice in a former mining area of Derbyshire and six of the interviewees were ex-miners, which may limit transferability of the findings. Additionally, data saturation may not have been reached and other themes may have emerged if participants from more than one practice were interviewed.

Bias was reduced by using patients from a neighbouring practice, where the interviewer was not a GP. However, response bias may mean that participants were motivated to join a pulmonary rehabilitation programme; their barriers to attending may differ from those who were not interviewed. It should also be noted that the researcher effect may have biased the replies given in the HADS form, leading to the under-reporting of anxiety and depression.

Twenty-five per cent of participants in this study had depression, a figure that is similar to that reported by van Manen *et al*<sup>20</sup> but lower than the previously reported 40–74% for COPD.<sup>10,21</sup> One explanation is that depression is 'diagnosed' in study participants by using questionnaires that vary in fidelity and reproducibility. Alternatively, patients who are depressed may be less likely to reply or participate in an interview, thus their views will be under-represented.

### **Comparison with existing literature**

Participants endeavoured to regain control by using their medication, limiting activity, and changing or adapting their behaviour — all actions that have been previously reported.<sup>8</sup> Loss of control may occur during an exacerbation or worsening of the underlying disease, or patients may feel that their agenda is not being heard. Factors that inhibit patients from regaining control are fear of breathlessness and exercise, lack of information about their disease, and therapeutic nihilism. These factors may be a result of poor communication or understanding about their disease and its treatment. The impact of pulmonary rehabilitation on pre-

existing illness, other commitments, and problems with transport were common concerns and have been previously reported.<sup>8,9,22</sup>

Differences have been reported in patients' typical handling of core chronic disease self-management tasks and skills. Passive self-managers usually defer to healthcare providers, feel compelled to relinquish valued roles, and have erratic or ineffectual emotional management skills, that is, relinquishing control. In contrast, active self-managers generally collaborate with healthcare providers, strive to maintain valued roles, and their emotional management includes conscious, regular use of coping strategies<sup>9</sup> (maintaining control). Expressions of loss were often mentioned by participants, resulting in changes in their interactions with the family, their social roles, and their ability to undertake activities that they had previously taken for granted. This has previously been reported.<sup>23</sup>

Chan<sup>24</sup> noted that patients used occupational therapy as a means of taking control of COPD and re-engaging in activities. Losing and regaining control is reported in patients with COPD,<sup>25</sup> those who undergo cardiac rehabilitation,<sup>26</sup> and those who suffer seizures.<sup>27</sup> Figure 1 illustrates the interplay between losing and regaining control in patients with COPD and shows how pulmonary rehabilitation may favour regaining control.

### **Implications for future research and clinical practice**

The value of pulmonary rehabilitation is not disputed, but ways of overcoming potential service users' barriers to using it need to be explored. One way of promoting its benefits may be explaining to patients that it can be a way of regaining control. The information gained from this study was used to develop a model (Figure 1) and to use with patients when making an offer of pulmonary rehabilitation. The authors propose a model where patients can be thought of as being in a dynamic situation between losing and regaining control.

When making an offer of pulmonary rehabilitation, if GPs can anticipate a patient's concerns, acknowledge, and then normalise them, they may be able to overcome the barriers that exist for some patients. By establishing the patient's goals and motivators, GPs may help implement the desired behaviour changes and assist the patients in regaining control.

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### Competing interests

The authors have stated that there are none. This work was submitted as part of an MSc thesis in evidence-based health care to the University of Oxford in 2007

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