

Why do people with chronic obstructive pulmonary disease repeat pulmonary rehabilitation? Perspectives of patients and health professionals

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Abstract

Many people with chronic obstructive pulmonary disease (COPD) undertake pulmonary rehabilitation more than once. This study examined patient experiences and health professional perspectives regarding repeating pulmonary rehabilitation. Participants were 14 patients with COPD and 15 health professionals. Patients had undertaken pulmonary rehabilitation at a tertiary hospital; health professionals were doctors, physiotherapists, and nurses. Semi-structured interviews were conducted, and data were analyzed using thematic analysis. Patients described improved fitness and better breathing after repeating pulmonary rehabilitation; however, some also reported that repeating required confronting their disease progression. Improved confidence and motivation were an important outcome of repeating. Although most participants had attended community-based exercise classes, they valued the greater intensity of exercise and closer supervision that came with repeating pulmonary rehabilitation. Health professionals reported referring patients to repeat pulmonary rehabilitation if they had worsening functional capacity, an exacerbation, or hospitalization. There was no agreement regarding the optimal time for repeating and many would only re-refer if the patient demonstrated motivation to attend. In conclusion, patients with COPD reported many symptomatic benefits from repeating pulmonary rehabilitation and gained confidence from a supervised program. There was no agreement between health professionals regarding the optimal time to repeat pulmonary rehabilitation.

Keywords

Pulmonary disease, chronic obstructive, quality of life, qualitative study

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Introduction

The benefits of pulmonary rehabilitation for people with chronic obstructive pulmonary disease (COPD) have been well-documented.¹ Pulmonary rehabilitation is an episodic intervention, with intense periods of supervision followed by unsupervised exercise training and a reliance on self-management.² Many people with COPD undertake pulmonary rehabilitation more than once, with a retrospective study suggesting that 20% will repeat within the first 2 years

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after program completion.³ The reasons for repeating pulmonary rehabilitation have not been examined. A small number of studies suggest that repeating is pulmonary rehabilitation beneficial; however, due to the limited number of participants in these studies, it is not clear whether the benefits are as great as for the first program.⁴⁻⁸ Previous studies examined repeating pulmonary rehabilitation after a time period of 6 months, 12 months, and 2 years,^{7,8} with one study randomizing patients into a modified 3-week program after an exacerbation within 12 months of their initial pulmonary rehabilitation program.⁵ None of these time points are clearly superior and the ideal timing for repeating pulmonary rehabilitation has not been defined. Guidelines for pulmonary rehabilitation suggest that patients could repeat pulmonary rehabilitation after 1 year, but this is based on expert opinion, and the authors acknowledge that timing may be influenced by the aim of re-referral.⁹ Little is known as to why health professionals re-refer patients to pulmonary rehabilitation or patient experiences of repeating the program.

The aim of this study was to better understand health professionals' reasoning for referring people with COPD to repeat pulmonary rehabilitation and to appreciate the experiences of repeating pulmonary rehabilitation for people with COPD. This information may assist in identifying the role of repeat pulmonary rehabilitation programs and the optimal time to re-refer.

Methods

This qualitative study used semi-structured interviews with open-ended questions. Participants had a diagnosis of COPD confirmed on spirometry and had undertaken an outpatient pulmonary rehabilitation program at a tertiary hospital at least twice within the previous 18 months. They were identified from a database of patients who had undertaken pulmonary rehabilitation. Potential participants were sent a letter inviting them to contact the investigators if they were interested in taking part. Information gathered from the medical history included age, gender, comorbidities, spirometry, confirmation of participation in pulmonary rehabilitation, and outcomes of pulmonary rehabilitation including 6-minute walk distance (6MWD) before and after the programs. We also recruited health professionals caring for people with COPD at two teaching hospitals, one an inner metropolitan hospital and one in the outer

Table 1. Interview questions for patients.

1. Can you tell me about your experience of doing the pulmonary rehabilitation program?
2. I understand that you have done the pulmonary rehabilitation program more than once. Can you tell me about the reasons why you repeated pulmonary rehabilitation?
3. Can you tell me about anything that was different when you repeated pulmonary rehabilitation, compared to the first time you did the program?
4. Can you tell me any ways in which your achievements were different after you repeated pulmonary rehabilitation compared to the first time you did the program?
5. Can you tell me about any ways in which you changed your approach to managing your lung condition after repeating pulmonary rehabilitation?
6. How often do you think it would be reasonable for someone with a lung condition to repeat pulmonary rehabilitation?
7. Would you recommend repeating pulmonary rehabilitation to other people with a lung condition?

metropolitan region. Health professionals were respiratory physicians, advanced medical trainees, physiotherapists, or nurses who had referred people with COPD to pulmonary rehabilitation. They were identified from staff lists at the participating hospitals and were invited to participate by e-mail. Participant interviews were conducted over the telephone or in person, according to the participant's preference and were audio recorded for accuracy. Telephone interviews were chosen to minimize the barriers to participation for people with COPD, who may find it difficult to travel to the center for a face-to-face interview due to disabling symptoms. A series of open-ended questions were developed based on a review of the literature and the experience of the investigators (Tables 1 and 2). Interviews were conducted by one of the investigators (SS) who has a background in nursing and health services management. The study was approved by the Human Research Ethics Committees of Alfred Health, Peninsula Health, and La Trobe University, and informed consent was obtained from all participants.

Data analysis

Recordings were transcribed verbatim. Two researchers independently analyzed the data using deductive thematic analysis.¹⁰ Line-by-line iterative thematic analysis took place with the development of

Table 2. Interview questions for health professionals.

1. When do you consider referring someone with a lung condition to pulmonary rehabilitation?
2. For a patient who has already done pulmonary rehabilitation, when would you consider referring them to repeat the program?
3. Are there any factors other than the patient's condition that would influence your decision to refer for a repeat course of pulmonary rehabilitation?
4. Can you tell me what kinds of benefits you expect when you refer a patient to repeat pulmonary rehabilitation?
5. In your experience, how acceptable/attractive is repeating pulmonary rehabilitation to patients?
6. Can you tell me any situations in which you would avoid a repeat referral to pulmonary rehabilitation?
7. What is your understanding of the scientific evidence regarding the benefits of repeating pulmonary rehabilitation?

descriptive codes to represent the data. Open coding commenced during the data collection and was used to compile a hierarchical coding scheme. Axial coding was then used to refine themes and understand the relationship of themes to subthemes. Finally, selective coding was used to understand the relationship between them. Discussion of themes took place until consensus was reached between the researchers. A third researcher provided peer debriefing. Additional strategies used to enhance the trustworthiness of data analysis were researcher memos, constant comparison to compare codes with newly transcribed data, diagramming to describe the relationship between themes, and documentation of theme naming. Quotations extracted from the transcripts provide supportive data. Data were analyzed separately for health professionals and patients. Data collection continued until saturation was reached in each group.¹¹

Results

Patient themes

Of the 29 eligible patients who were sent a letter of invitation, 14 patients were interviewed. Participants with COPD were aged 45–90 years and 50% were male. The majority had undertaken pulmonary rehabilitation more than twice (range 2–5 programs). Demographic characteristics are presented in Table 3. On average, interviews lasted 22 minutes. Data saturation was evident after 12 interviews. Themes that emerged from the interviews are listed in Table 4.

Participants with COPD were all extremely positive about the benefits of pulmonary rehabilitation for their health. Some reported benefits included improved fitness, better breathing, greater confidence in their ability to undertake activities of daily living, weight loss, and increased motivation:

P013: It's a positive message that you are actually getting... I find physically and mentally the rehabilitation program is excellent.

External drivers to repeat pulmonary rehabilitation

Patients reported a variety of reasons for repeating pulmonary rehabilitation, most relating to external drivers rather than a personal motivation:

P008: Yes I got sick and went back to hospital and I was referred back to do the program again because I was having problems with my mobility and my breathing capacity.

Many reported that a health professional recommended repeating due to changes in their health status:

P003: It was the lung specialist... probably because there has been some change in my condition.

Others said they repeated pulmonary rehabilitation due to a change in their physical fitness or breathing:

P003: ... it may not be possible to restore the level of fitness that was there before, but to recoup some of the lost level of fitness due to my not having participated.

Diversity of experiences when repeating pulmonary rehabilitation

Some participants found no differences between the first and second rehabilitation programs. Others said it was easier the second time, primarily because they knew what to expect and were more confident. Another group of participants reported that repeating pulmonary rehabilitation meant confronting the deterioration in their health since the previous program, revealing a decline in their physical capacity. As a result, these participants had lowered their expectations of what they could achieve after repeating pulmonary rehabilitation:

P014: I do notice a difference, they put me on oxygen now when I'm exercising, where as previously I wasn't.

Table 3. Demographics of patients.

ID	Gender	Age (years)	Interval between programs (months)	FEV ₁ % predicted PR 1	FEV ₁ % predicted PR 2	6MWD pre/post PR 1 (m)	6MWD pre/post PR 2 (m)	Comorbidities
P001	Female	65	18	47	53	321–372	400–360	Mild-to-moderate pulmonary hypertension, pulmonary embolus
P002	Male	69	8	33	36	460–473	405–445	Hypercholesterolemia
P003	Male	80	14	71	65	435–500	225–292	Hypertension, fibromyalgia, depression, ex-smoker
P004	Female	70	16	51	44	430–418	330–370	Pulmonary fibrosis, ex-smoker
P005	Male	90	12	45	NA	417–495	300–380	Atrial fibrillation, stroke, congestive cardiac failure, peripheral vascular disease, gout, prostate cancer
P006	Male	66	18	33	39	375–390	395–400	Chronic renal failure (dialysis), hypertension, stroke, anxiety
P007	Female	86	18	43	42	237–313	282–335	Rheumatoid arthritis, breast cancer
P008	Male	63	18	82	51	394–430	359–370	Cardiac failure, diabetes
P009	Female	45	24	45	40	339–348	339–359	Bronchiectasis, depression, asthma
P010	Female	70	45	64	57	432–395	350–477	GORD
P012	Male	73	6	51	56	235–246	274–333	Skin cancer, diverticulitis
P013	Female	56	24	52	36	NA	385–413	Osteoporosis, GORD
P014	Male	75	24	55	57	322–DNC	233–257	Obstructive sleep apnea, chronic lymphocytic leukemia
P015	Female	74	24	44	50	347–435	369–365	Obesity, hypertension, osteoporosis

6MWD: 6-minute walk distance; DNC: did not complete; FEV₁: forced expiratory volume in 1 second; GORD: gastroesophageal reflux disease; NA: not available; PR: pulmonary rehabilitation.

P007: In myself I'm not as good as I used to be . . . I've gone downhill and I can't expect to come back to where I was before unfortunately.

Other exercise programs are not the same as pulmonary rehabilitation

Many participants commented on the differences between the pulmonary rehabilitation program and other programs they had attended in the community. The differences included reduced frequency of community programs, lower intensity of exercise training, a smaller range of equipment, and less supervision:

P008: I don't think I get as much out of it (the community exercise program) but I'm doing it because I'm still struggling with my breathing.

P012: . . . pulmonary rehab is specialised and it monitors you much more closely.

Benefits of repeating pulmonary rehabilitation are due to supervision

Nearly all of the participants discussed how much easier it was to maintain a meaningful exercise

regimen when supervised. They were more motivated to exercise regularly, confident with being monitored during the sessions and found it a disciplined way of maintaining regular exercise:

P006: Often I'd be at the pulmonary gym . . . I'd be on the treadmill thinking if I was at home I would have stopped now . . . So it's motivation to keep doing it.

A number of participants reported the importance of external motivators to continue with exercise:

P008: . . . I find when I go walking if I have the dog it sort of gives me more purpose as well, it's . . . easier to drag yourself out of the door.

Desire to undertake pulmonary rehabilitation more frequently than offered

Many participants wanted to undertake pulmonary rehabilitation more frequently than it had been offered to them, with some preferring continuous involvement:

P012: I think you have to do it all the time . . . the only remedy for the condition is to have exercise and try to build up the lungs.

Table 4. Themes from patient interviews.

Pulmonary rehabilitation was beneficial
– Improved fitness
– Better breathing
– Improved confidence
– Weight loss
– Positive messages
Reasons for repeating pulmonary rehabilitation
– External drivers to repeat
– Symptoms worsened
– After hospital admission
– Health professionals suggested it
– Because of a change in physical fitness
– No self-referrals
Diversity of experience of repeating pulmonary rehabilitation
– Fitter and more confident, knew what to expect
– No difference from initial experience
– Highlighted deterioration in physical condition since last time
Other exercise programs are not the same as pulmonary rehabilitation
– Frequency, intensity, equipment, degree of supervision
Benefits of repeating pulmonary rehabilitation under supervision
– Motivation
– Monitored during exercise
– External motivator for ongoing exercise
– Discipline
Desire to repeat pulmonary rehabilitation more often than offered
– Continuous
– Depends on health service resources

Nevertheless, many participants were mindful of the pulmonary rehabilitation program being a limited resource and other people would benefit from the service:

P003: . . . I'm very conscious of the fact, there are (only) so many places available. I would not like to be taking the place of someone else whose needs are greater or equal to mine.

Health professionals

Fifteen health professionals were interviewed, from a total of 25 e-mail invitations sent. Participants comprised seven doctors, six physiotherapists, and two nurses. Two doctors were in their final year of specialist physician training and the remainder had between 5 and 18 years of experience as a respiratory physician. Physiotherapists and nurses had between 2 and 25 years of experience in delivering respiratory

Table 5. Themes from health professional interviews.

Triggers for repeat referral
– Change in function
– Quality of life
– Not maintaining an exercise program
– Symptomatic
– Exacerbation of COPD
– Hospitalization
Expected benefits from repeating pulmonary rehabilitation program
– Improved self-management
– Functional gain
– Managing patient expectations
– Stability of lung condition
– Improved quality of life
The optimal time to repeat
– A defined time after the initial program
– Individual decision
– Decrease in quality of life, symptomatic
– If the patient did not complete the first time
– If the patient is not maintaining exercise program
Barriers to repeating
– Logistics, transportation, geographical location, financial situation
– Living circumstances; assisted accommodation
– Motivation of participant
– Service capacity
Scientific evidence
– Insufficient evidence around repeating pulmonary rehabilitation
– No written guidelines
Not to refer when . . .
– For purely psychological benefit
– Comorbidities overwhelming
– Severely impaired mobility or cognition

COPD: chronic obstructive pulmonary disease.

services, including two physiotherapists who led pulmonary rehabilitation programs. All had made referrals to pulmonary rehabilitation for patients with COPD. On average, interviews lasted 14 minutes. Data saturation was evident after 14 interviews. Themes are listed in Table 5.

All health professionals strongly supported the role of pulmonary rehabilitation in the management of COPD. The top reasons for referring patients with COPD for their first program were upon diagnosis of COPD, symptoms of COPD impacting on their life, functional decline, and acute exacerbation of their lung condition.

C011D: If they have significant functional limitations and if they're interested in and willing to participate in a pulmonary rehab program.

Triggers for referral to repeat pulmonary rehabilitation

Health professionals re-referred patients with COPD to pulmonary rehabilitation when there was a change in their functional status or exercise capacity:

C001P: ... if they (patients) are able to articulate ... a change from what they were capable of doing in the past then that's often a motivating factor for people to come again.

A large number of health professionals reported that if patients were not maintaining their exercise program, they would re-refer to pulmonary rehabilitation.

C012D: ... if they ... have noticed a decrease in their exercise tolerance and they are not on a structured exercise program.

All health professionals acknowledged that acute exacerbations impact on functional capacity and frequently trigger re-referral. If patients with COPD had been hospitalized for a condition other than their lung disease, many health professionals used this as an opportunity to re-refer:

C012D: ... if they have been in hospital ... and they have become deconditioned, I probably would (refer to repeat).

Benefits from repeating pulmonary rehabilitation

Reengagement in pulmonary rehabilitation aimed to improve functional capacity and promote self-management, through the educational element of the program and by interaction with program staff.

C003P: ... the education that's involved with pulmonary rehab is quite priceless in terms of their self-management; keeping them out of hospital for longer is a big benefit.

Some health professionals recognized that regularly repeating pulmonary rehabilitation was a means of avoiding crisis management:

C006 N: I think they are having like tune-ups ... I think it could prevent the referral becoming urgent ...

A small number of health professionals spoke of the negative impact of patients relying on a formal pulmonary rehabilitation program:

C004P: ... the whole point of pulmonary rehab is we improve self-management and self-care at home. We don't want to then become their sort of crutch to lean on as well.

Magnitude and nature of benefits from repeating pulmonary rehabilitation

There were varied expectations from the health professionals as to the likely outcomes and magnitude of benefit from repeating pulmonary rehabilitation.

C001P: ... thinking about what benefit someone will get you're obviously hopeful that it will be what they had in the past but you're ... mindful of the fact that it's a deteriorating lung condition.

C010D: ... this is probably fanciful but I think they would be similar (to the initial program) ... Well, maybe I hope they would be similar.

Some health professionals acknowledged the impact of disease progression on pulmonary rehabilitation outcomes.

C004P: ... they say, I didn't do as well this time as I did before. But that said, I think they are still grateful for coming. I think they know their rate of decline probably would be rapider if they hadn't come.

Determining the optimal time to repeat pulmonary rehabilitation

There was no agreement among the health professionals, irrespective of their profession, as to the optimal time for repeating pulmonary rehabilitation. Opinions varied from after 6 months to a year, definitely not within the year, consider re-referring after 1 year, to an annual referral if the patient has not been in a program for 4–5 years.

C009D: Completely without any classification I think of it as an annual thing.

A number of health professionals felt that repeating was an individual decision for the patient, depending on their requirements and motivation:

C007P: No, every patient, person is totally different. Totally individual choice of the patient.

Patients should only be referred for repeating pulmonary rehabilitation if they are motivated to attend

The majority of health professionals considered patient motivation as a guide to whether they would re-refer to pulmonary rehabilitation:

C008P: . . . Unless they are motivated it is actually very unlikely personally that I will re-refer.

Practical barriers to repeating pulmonary rehabilitation

Health professionals were very aware of the barriers to repeating pulmonary rehabilitation, which included transportation, finances, disability limiting travel, cognitive capacity, and language barriers:

C011D: . . . often I think they find leaving the house difficult in terms of the physical aspects of transport. If they don't drive a car and public transport is difficult for them then they are often very reluctant . . .

Insufficient scientific evidence regarding the benefits of repeating pulmonary rehabilitation

All health professionals were aware of literature supporting the value of pulmonary rehabilitation, but only a handful had any knowledge of the few papers focusing on repeating the program.

Discussion

This study has shown that patients with COPD experienced a wide variety of benefits from repeating pulmonary rehabilitation, many of which they attributed to the motivation and confidence they gained from exercising under supervision. However, the experience of repeating pulmonary rehabilitation was confronting for some in whom it revealed a physical deterioration since their last program. Most would have liked to repeat pulmonary rehabilitation more often than it was offered; however, they were mindful that it was a scarce resource. There was no agreement among health professionals regarding the optimal time or frequency for repeating pulmonary rehabilitation, with triggers for repeat referral including a reduction in functional capacity, failure to engage in a regular exercise program, and recent exacerbation or hospitalization. Health professionals were unsure about the expected gains from repeating pulmonary rehabilitation but emphasized the importance of patient motivation in the decision to re-refer.

Consistent with the variation in outcomes seen in quantitative studies,^{4–8} patients reported a variety of outcomes from repeating pulmonary rehabilitation. Some felt they attained similar benefits to the initial program and some found they gained more from the repeat program as they knew what to expect.

Unexpectedly, some patients said that repeating pulmonary rehabilitation required them to confront the deterioration in their health. This has not previously been documented and did not emerge in our interviews with health professionals. Health professionals who run pulmonary rehabilitation should be aware of this common experience which may affect motivation and ability to engage with repeat programs. The referring health professionals also had a variety of expectations for the outcomes of repeat pulmonary rehabilitation and acknowledged that there was limited science to inform them on this topic.

Many patients reported that they had engaged in other exercise programs after completing pulmonary rehabilitation but were dissatisfied with their experiences due to differences in program content, format, and supervision. Many saw the supervision offered in a pulmonary rehabilitation program as a unique feature, providing confidence and motivation. Pulmonary rehabilitation is an episodic intervention, with intense periods of supervision, followed by unsupervised exercise training or a maintenance program with lower intensity of supervision. One of the goals of pulmonary rehabilitation is for patients to acquire the necessary skills to actively manage in their own care, achieving a degree of independence from health professionals.² This includes the maintenance of a personal activity program. However, our data suggest that many participants felt unable to sustain this over time. Health professionals also confirmed this pattern, with failure to maintain an exercise program being a major reason for re-referral. Recent data suggest that improvements in daily physical activity following pulmonary rehabilitation may be marginal, despite significant gains in exercise capacity,¹² suggesting that improved physical fitness does not necessarily translate to adoption of healthy behaviors. Repeating pulmonary rehabilitation may have an important “booster” role for physical health, motivation, and self-management skills. The cost-effectiveness of an approach to COPD care which involves regularly repeating pulmonary rehabilitation has not been investigated to date.

There was no agreement among health professionals regarding the best time to repeat pulmonary rehabilitation. Previous studies have shown that the benefits of pulmonary rehabilitation decline over the first year following program completion, with exercise capacity declining more rapidly than health-related quality of life.^{2,7} Measures such as 6MWD may provide a useful clue as to when a repeat program

should be offered to an individual. While previous studies of repeating pulmonary rehabilitation have trialed a number of time points,^{7,8} it does not appear that any one approach is superior. However, the conclusions that can be drawn from previous studies are limited by low numbers of participants and, in some cases, uncontrolled designs.

The strengths of this study lie in the rich data extracted from the interview process. Health professionals were able to express their clinical reasoning regarding re-referral to pulmonary rehabilitation. We only interviewed patients who had repeated and did not obtain information from people with COPD who had declined to repeat; this is a limitation as the perspectives of those who choose not to repeat are not included and our participants may have been more positive about the benefits of repeating. All health professionals were recruited from teaching hospitals and were supportive of referral for repeat pulmonary rehabilitation. It is possible that their views and experiences do not reflect those of health professionals in other settings.

In conclusion, people with COPD value the opportunity to repeat pulmonary rehabilitation and gain confidence from a supervised program. There is no agreement among health professionals regarding the optimal time for repeating. Given the importance placed on repeating pulmonary rehabilitation by both patients and health professionals, future studies could investigate models of COPD care that involve regularly repeating pulmonary rehabilitation, including the cost-effectiveness of such an approach.

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