Lack of perceived benefit and inadequate transport influence uptake and completion of pulmonary rehabilitation in people with chronic obstructive pulmonary disease: a qualitative study

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Question: What prevents people with chronic obstructive pulmonary disease (COPD) from attending and completing pulmonary rehabilitation programs? Design: Qualitative design using semi-structured interviews. Participants: 19 adults with COPD who had declined to participate and 18 adults with COPD who had not completed a pulmonary rehabilitation program at a metropolitan teaching hospital. Results: A lack of perceived benefit from pulmonary rehabilitation was a significant theme for those who chose not to participate in pulmonary rehabilitation. Participants expressed perceptions that exercise was not a worthwhile treatment, or that they were already doing enough exercise at home. Difficulty getting to the program related to poor mobility, lack of transport, and cost of travel was a significant theme, expressed both by those who chose not to participate and those who did not complete. Another major theme associated with both uptake and completion involved being unwell, with participants indicating that the burden of COPD and other comorbidities impacted on attendance. Minor themes involved competing demands on time, older age, fatigue, program timing, and lack of social support. Conclusion: Many people with COPD who elect not to take up a referral to pulmonary rehabilitation perceive that they would not experience any health benefits from attendance. Difficulties with travel to the program and being unwell are barriers to both uptake and completion. Improving attendance at pulmonary rehabilitation requires consideration of how information regarding the proven benefits of pulmonary rehabilitation can be conveyed to eligible patients, along with flexible program models that facilitate access and accommodate co-morbid disease.

Key words: Pulmonary disease, chronic obstructive, Pulmonary rehabilitation, Physical therapy, Patient adherence, Qualitative research

Introduction

Chronic obstructive pulmonary disease (COPD) is characterised by shortness of breath on exertion, marked disability and frequent hospitalisation. Health system costs are estimated at $800–900 million per annum in Australia, the majority of which is attributable to hospital use (Australian Lung Foundation 2008). There is Level 1 evidence that pulmonary rehabilitation improves exercise capacity, reduces breathlessness, and improves quality of life in people with COPD, regardless of disease severity (Lacasse et al 2006). Pulmonary rehabilitation also reduces acute exacerbations and hospital admissions (Guell et al 2000).

Despite the known benefits of pulmonary rehabilitation, many people with COPD who are eligible for the program choose not to participate. Existing data suggest that between 8% and 50% of those who are referred to a program never attend, whilst 10–32% of those who commence a program do not complete (Keating et al 2011). The barriers to participation in pulmonary rehabilitation are not well documented. Travel requirements, illness, disruption to routines, low perception of benefit, and depression may be important factors (Keating et al 2011). However, most studies are small (Arnold et al 2006, Fischer et al 2007), have examined non-completion of programs that are conducted in the context of clinical trials (Fan et al 2008, OShea et al 2007, Taylor et al 2007), or have not differentiated those who chose not to attend at all from those who do not complete (Fischer et al 2009). There is a paucity of data regarding patients who are referred but never attend. More information regarding barriers to both uptake and completion is required in order to enhance participation in this important and effective intervention.

The research questions addressed in this study were:
1. What are the barriers to uptake of pulmonary rehabilitation for people with COPD?
2. What are the barriers to completion of pulmonary rehabilitation for people with COPD?

Method

Design
A qualitative study using semi-structured interviews was undertaken based on the principles of grounded theory (Boeije 2002, Strauss and Corbin 2007). Participants were interviewed within one month of declining to participate in or withdrawing from a pulmonary rehabilitation program.
Participants

Individuals in this study were patients who had been referred to a pulmonary rehabilitation program and either did not attend their initial appointment or failed to complete the program. Failure to complete was defined as ceasing to attend scheduled sessions prior to the end of the program and failure to undertake the final assessment. The study was conducted at a tertiary hospital, located in an inner metropolitan area. Parking was available for a fee and a limited volunteer driver program was offered to patients who could not otherwise access the hospital. The pulmonary rehabilitation program followed a standard format (Nici et al 2006), with seven weeks of twice-weekly group exercise and self-management education sessions. The exercise component was individually prescribed and consisted of 30 minutes of aerobic training (walking and exercise bike) with intensity progressed weekly, and resistance training using functional tasks such as step ups and sit to stand. Sessions were conducted in the morning.

Patients were included in the study if they had a diagnosis of COPD and were aged 18 years or over. Patients were excluded if they did not speak English and could not participate in an interview. Individuals who were eligible to take part were contacted by an independent investigator not involved in delivery of the clinical program who provided written information and obtained consent.

Measures

Nine interview questions were developed (Box 1) and reviewed by two experts in the delivery of pulmonary rehabilitation programs. The questions allowed exploration of possible reasons for and individual experiences associated with non-attendance and non-completion. All participants who undertook the semi-structured interview were given the option of doing it at their home or over the telephone. Interviews were recorded and took 20–40 minutes to complete. Researcher triangulation was employed, with interviews conducted by one of two researchers (AK or AH) in order to reduce the potential for bias (Patton 1999). Researchers were encouraged to make observational memos for use during analysis (Boije 2010). Each interview was transcribed verbatim by a single researcher. If clarification was needed on the content or meaning of an interview the participant was contacted to review the information. Demographic information collected directly from participants and from their medical record was gender, age, body mass index (BMI), lung disease severity using the Global Initiative for Obstructive Lung Disease (GOLD) criteria (Rabe et al 2007) based on recent (within six months) spirometry, smoking status, home oxygen use, living situation, comorbidities score (Charlson et al 1987) and distance between their home and the pulmonary rehabilitation venue.

Data analysis

De-identified interview transcripts were examined independently by two researchers (AK and AH). Line-by-line iterative thematic analysis (Boyatzis 1998) of the transcribed interviews took place, where descriptive codes were devised to represent the data. Three rounds of coding were used. Open coding commenced during data collection and was used to compile a hierarchical coding scheme. Axial coding was then used to refine and delineate the relationship of themes to subthemes. Major themes were considered to be those themes where subthemes arose (Boije 2010). Finally, selective coding was used to explore connections between themes and select the core category (Strauss and Corbin 2007). Theoretical memos were used during analysis to reflect how findings were derived from the data (Boije 2010). Discussion of the themes took place until a consensus was reached between the two researchers, with the third researcher (AL) providing peer debriefing. Quotations were extracted from the transcripts to provide supportive data for each theme. Recruitment and data collection continued until saturation was achieved (Guest et al 2006).

Results

Over the study period (November 2008 to June 2009) 71 patients were referred to The Alfred Hospital Pulmonary Rehabilitation program and 21 patients (30%) declined to attend. Non-completion data were collected between January and December 2009, during which time 21 patients did not complete the program. Two individuals (one non-attender) were excluded as they were not able to speak sufficient English, and three individuals declined the invitation to participate. Nineteen non-attenders and 18 non-completers agreed to be interviewed. The demographic features of the participants are contained in Tables 1 and 2. Twenty-one interviews were conducted by telephone (11 non-attenders) and the remaining sixteen interviews (eight non-attenders) were conducted in person, with no differences in emergent themes identified between the two methods. Themes emerging from the interviews for non-attenders and non-completers are compared in Table 3.
Table 1. Demographic characteristics of participants who did not attend pulmonary rehabilitation

<table>
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<tr>
<th>Participant number</th>
<th>Gender</th>
<th>Age (yr)</th>
<th>BMI</th>
<th>GOLD stage</th>
<th>Current smoker</th>
<th>Home oxygen</th>
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BMI = body mass index, GOLD = Global Initiative for Obstructive Lung Disease classification of disease severity, PR = pulmonary rehabilitation

Table 2. Demographic characteristics of participants who did not complete pulmonary rehabilitation.

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BMI = body mass index, GOLD = Global Initiative for Obstructive Lung Disease classification of disease severity, PR = pulmonary rehabilitation
Participants who did not attend pulmonary rehabilitation at all

Ten women and nine men, with GOLD stages ranging from mild (Stage I) to very severe (Stage IV), declined to attend pulmonary rehabilitation at all. Twelve out of the 19 participants lived alone. Over half of the participants (n = 10) stated that they were not given any information upon referral to the pulmonary rehabilitation program regarding what would take place there. Five participants had no memory of being referred to a pulmonary rehabilitation program.

I don’t remember being referred to one, because if I remember being referred to one, I would have joined it. (P2)

Major themes associated with non-attendance

Getting there: Twelve participants stated that getting to the pulmonary rehabilitation venue was difficult, with nine indicating that travelling to the venue for pulmonary rehabilitation prevented their attendance. These participants were not able to access a car or public transport:

I just can’t make it because I have no car and I have to walk all the way down to X Rd; that takes me about half an hour. (P3)

Three participants stated that they would attend if they could be picked up and returned home by a transport service:

I certainly would attend if there was some arrangement where they could pick me and drop me off back home. (P7)

Six patients indicated that their limited physical mobility and reliance on gait aids was a barrier to attending pulmonary rehabilitation:

If I ever go out I always have to go in the wheelchair. (P8)

The cost associated with travel was raised by five participants, who indicated that getting to the program via a taxi was too expensive:

I have to take a taxi each time and you know it is costing a fair bit of money; I’m only on a pension. (P18)

Lack of perceived benefit: Eleven participants reported that they did not consider that pulmonary rehabilitation would have any health benefits for them. This was associated with perceptions of the worth of exercise as a treatment:

It is not as if I get some treatment or something; I mean it is just physical exercise, nothing else. (P3)

Some individuals (n = 4) felt they were doing enough exercise on their own and therefore did not need to attend the program. Three patients felt they knew all of the exercises that would be performed at the pulmonary rehabilitation program:

I do all the exercise like you do there you know. (P4)

Being unwell: The burden of COPD and other comorbidities influenced the decision not to attend pulmonary rehabilitation. Four participants felt their respiratory condition would have to improve before they could attend:

My breathing on exertion would have to get better. (P17)

Five participants indicated that other medical conditions contributed to their failure to attend. These patients did not consider COPD to be their most significant health issue and expressed fear of exacerbating other medical conditions:

Data are themes and subthemes, and number of participants contributing data to each theme. COPD = chronic obstructive pulmonary disease
Six participants identified other non-respiratory problems that had prevented them from completing the program. These comments reflected the relative importance ascribed to pulmonary rehabilitation compared to other demands, or the number of demands being managed. Five participants said they were too old to attend pulmonary rehabilitation, including two patients who thought they did not have long to live. Five participants felt that the energy levels required to attend pulmonary rehabilitation would be too much for them. Four participants commented that the timing of the program affected their ability to attend, with three of these indicating the program was too early in the day.

Minor themes associated with non-attendance

Competing demands were associated with non-attendance by five participants. Overseas travel, seeking new accommodation, the burden of other medical treatments such as nebulisation and oxygen therapy, the need to care for pets, and not wanting to leave their residence unattended were all reported. These comments reflected the relative importance ascribed to pulmonary rehabilitation compared to other demands, or the number of demands being managed. Five participants said they were too old to attend pulmonary rehabilitation, including two patients who thought they did not have long to live. Five participants felt that the energy levels required to attend pulmonary rehabilitation would be too much for them. Four participants commented that the timing of the program affected their ability to attend, with three of these indicating the program was too early in the day.

Participants who did not complete pulmonary rehabilitation

Nine women and nine men did not complete pulmonary rehabilitation (Table 2), attending between 1 and 12 sessions. Five of the participants had utilised volunteer transport to attend the program. Six of the eighteen non-completers stated that they did not know why they were referred to pulmonary rehabilitation, whilst two participants reported that they were referred because of non-respiratory conditions (heart attack and weight loss). Ten participants indicated that they would like to complete a pulmonary rehabilitation program in the future:

I think it would be great actually. What I need to do is build up my breathing and my fitness so I think from when I attended that it would help. (P34)

Major themes associated with non-completion

Being unwell: Fifteen individuals identified specific health problems that had prevented them from completing the program. The most commonly identified health problem, reported by nine participants, was pain in the legs or spine. This pain arose from a number of different causes and participants generally associated it with pre-existing conditions:

Yes, it’s painful because the blood clot is there; I have a blockage in my vein, I refuse the operation because I am too old for operation. (P33)

Well when you’ve got osteoarthritis you’ve got bone on bone, and of course it’s painful. (P36)

Two participants reported episodes of new pain (sprained ankle and acute back pain), the onset of which they attributed to activities undertaken in caring for others:

I was looking after my grandchildren and it’s quite possible that I picked my grandson up the wrong way. (P34)

Six participants identified other non-respiratory problems that contributed to their inability to complete the program:

I don’t think the emphysema is the worst of my problems by any means. (P13)

I am just frightened that if I go I could do more damage to my neck than anything. (P8)

Well sometimes it is because my thyroid doesn’t work so I get very tired. And I also have diverticulitis which doesn’t help sometimes. (P37)

I had to drop off because I had to go into X hospital for a renal operation. (P23)

Four participants reported that an exacerbation of COPD prevented their completing pulmonary rehabilitation:

Because my chest was very bad we sort of put it off for a month and then I just never got around to going back again. (P22).

Getting there: Six participants indicated that travelling to the pulmonary rehabilitation venue prevented their ongoing attendance. Multiple barriers were discussed within this theme, including a lack of transport options, inconvenient timing of transport, poor mobility, and cost:

Well, I don’t have a car myself, and as you know I can’t get onto public transport because my legs just won’t let me. I’ve got a walker now. I’ve got to rely on taxis and that gets a bit expensive. (P28)

Oh, one of the other things I do have a problem with is parking. It’s $X every time you go there. That’s very expensive when you’re on a pension. (P37)

Five participants indicated that they would only be able to complete pulmonary rehabilitation if they could undertake the program in their own home. For some participants this was to avoid the burden of travel, whereas for others it was because they felt more secure in their own environment:

Yes, (if) that program (could be at) my place it can be help, but not in the hospital. (P33)

I feel much more secure at home than anywhere else. (P32)

Minor themes associated with non-completion

Four participants indicated that the program was too early in the day, whilst one participant who had returned to work indicated that he would be more likely to complete the program if it were to run outside of working hours. Four participants indicated that they felt too tired to complete the program, either due to general fatigue or because the exercise program increased their feelings of fatigue. Four participants indicated that they didn’t feel any benefit from attending the program. These participants had attended between one and four sessions before withdrawing. Three participants indicated that living alone and a lack of supportive family or friends had contributed to their failure to complete the program. Competing demands in the form of family responsibilities, work responsibilities, and the burden associated with managing multiple chronic diseases were cited by three participants.

Ascribing value to pulmonary rehabilitation

For both non-attenders and non-completers, the core category emerging from the interviews was Ascribing Value to pulmonary rehabilitation. Participants described how they apportioned value to attending pulmonary rehabilitation in the context of other aspects of their lives, including important activities, treatment burden, disease burden, and costs. Three attitudes towards Ascribing Value
were evident. Participants who ascribed minimal value to pulmonary rehabilitation had no expectation that it could bring health benefits. These participants were predominantly non-attenders and did not foresee any improvements in their health status in the future, regardless of treatment. A larger group of participants described low relative value of pulmonary rehabilitation, where the potential benefits of pulmonary rehabilitation were acknowledged but outweighed by other significant values, burdens, and costs. These participants described barriers to their attendance as overwhelming and unable to be overcome. The final group understood pulmonary rehabilitation to be of high relative value and anticipated that completion of pulmonary rehabilitation would result in health benefits. These participants, who were predominantly non-completers, described present barriers to attendance but could envision scenarios in which these barriers were overcome, such as improvement in their health status, provision of transport, or availability of home-based pulmonary rehabilitation.

**Discussion**

This study is the first to make a direct comparison of barriers to uptake and to completion of a pulmonary rehabilitation program. It demonstrated that the major themes associated with choosing not to attend were difficulties with getting there, a lack of perceived benefit, and limitations imposed by underlying medical conditions. The majority of participants who chose not to attend at all felt that they had little information regarding what occurred in a pulmonary rehabilitation program. Being unwell was the strongest theme associated with non-completion of the program, although travel and transport were also important. Despite these barriers, many participants who did not complete ascribed high value to the pulmonary rehabilitation program and stated that they would like to complete it in the future.

Eleven of the 19 patients who elected not to attend did not perceive there would be any benefit from participating in pulmonary rehabilitation, indicating limitations related to either the delivery or comprehension of information regarding the well-documented benefits of pulmonary rehabilitation for COPD. All participants were referred by either a respiratory physician or a physiotherapist and had received written educational material concerning pulmonary rehabilitation at the time of referral. Strength of referral is one of the most powerful determinants of a patient’s participation in rehabilitation (Ades et al 1992), reinforcing the need for clinicians to articulate the potential benefits of treatments clearly. Low levels of health literacy have been documented in people with COPD (Press et al 2011) which may impact on the effectiveness of written information. However, it has recently been demonstrated that even when high quality, specific information about pulmonary rehabilitation is delivered, using current best practice regarding information presentation and terminology, there may not be improvements in COPD care (Harris et al 2009). This suggests that information alone is insufficient to change behaviours. Data from this study suggest that there is a group of patients who see pulmonary rehabilitation as of minimal value who also have low expectations regarding their future health status, and thus may not consider that the potential benefits of rehabilitation might apply to them. Further consideration is needed of how best to convey the potential benefits of pulmonary rehabilitation to those who are eligible to attend. Such strategies could include utilising peer support and education delivered by others with COPD who have personal experience of the program.

More than half of the participants in this study indicated that difficulty in getting to the pulmonary rehabilitation venue affected their decision to participate, despite the fact that the vast majority lived less than 10 km from the hospital. Both the availability and the cost of transport were cited as barriers to attendance. Over half of the participants lived alone and many relied on public transport or family and friends to attend pulmonary rehabilitation. Although a volunteer driver program was in place at the hospital where the pulmonary rehabilitation program took place, this had limited capacity and was clearly insufficient to overcome the burden of travel. These results are consistent with previous reports examining attendance at pulmonary rehabilitation (Fischer et al 2007, Taylor et al 2007, Young et al 1999). Current pulmonary rehabilitation guidelines do not make strong recommendations regarding transport, recognising the cost implications for clinical services (British Thoracic Society 2001). Other guidelines suggest that patients with limited access to transport undergo pulmonary rehabilitation as an inpatient (Nici et al 2006), however this is not available in many settings – including our own. Given the consistency with which travel and transport have been reported as barriers to attendance, this issue requires attention in future program models.

A number of participants who did not complete the pulmonary rehabilitation program expressed a preference for programs conducted in the home environment. This was related to both the challenges of travel and the greater feeling of security associated with being at home. Previous research has shown that home-based pulmonary rehabilitation results in clinically meaningful benefits for people with COPD when compared to no-treatment control groups (Fernandez et al 2009, Hernandez et al 2000, Strijbos et al 1996). However, many home-based program models have required multiple home visits from health professionals and are therefore expensive to run, resulting in limited uptake in the clinical setting. A large study, powered for equivalence, has recently shown similar outcomes for self-monitored home pulmonary rehabilitation and hospital-based outpatient pulmonary rehabilitation for people with moderate to severe COPD (Maltais et al 2008). If these benefits of home-based, unsupervised pulmonary rehabilitation can be reproduced at a reasonable cost, this may be a feasible method for overcoming one important barrier to attendance at outpatient pulmonary rehabilitation programs.

Fifteen out of 18 participants who did not complete the program reported that becoming unwell had affected their ability to participate. Surprisingly few of these participants had an exacerbation of their lung condition, with other medical conditions reported more frequently. Most patients undergoing pulmonary rehabilitation have one or more comorbidities and this may limit the benefits that can be attained, even in those who can complete the program (Crisafulli et al 2008). Pain related to other medical conditions was the most commonly reported comorbidity influencing completion in this study. The pain experiences in people with COPD have been studied infrequently, with most data gathered from people with endstage disease (Lohne et al 2010). The current study suggests that pain may be experienced by people with COPD across the range...
of disease severity and should be taken into account during program design and patient assessment. Alternative models for pulmonary rehabilitation such as water-based exercise (Rae and White 2009) may be appropriate for some patients in whom pain limits participation. Given that most of those participants who could not complete the program ascribed high value to pulmonary rehabilitation and expressed a desire to complete it in the future, flexible program models are required that allow those who become unwell to rejoin a suitable pulmonary rehabilitation when they are able to do so.

A strength of this study is that a significant number of participants who chose not to attend pulmonary rehabilitation at all were included. These patients have been included infrequently in previous studies and this is the largest study examining barriers to uptake of a clinical pulmonary rehabilitation program which is representative of usual care (Arnold et al 2006, Fischer et al 2007). Themes emerging from this study show that while most of the barriers to uptake are similar to those for completion, a lack of perceived benefit has an important role in the decision to commence a pulmonary rehabilitation program; this theme was much less evident amongst non-completers, who had some experience of attending a pulmonary rehabilitation program.

A limitation of this study is that it involved only patients who failed to attend or complete a pulmonary rehabilitation program at a metropolitan teaching hospital in Australia. There may have been a selection bias due to the nature of the institution and the characteristics of the region where participants were recruited. The themes regarding non-attendance in this study are not applicable to pulmonary rehabilitation programs located in other settings, such as community-based programs conducted in health centres or community halls. As patients were excluded if they could not speak English this study may not be representative of all individuals within the community and may not reflect cultural reasons that may exist for non-attendance.

In conclusion, many individuals who elected not to take up a referral to pulmonary rehabilitation perceived that there would be no health benefits from undertaking the program. Transport and travel were important barriers to both uptake and completion, related to lack of transport, cost of travel, and poor mobility. Being unwell was an important limitation to completion of the program. Improving uptake and completion of pulmonary rehabilitation requires new methods for conveying the proven benefits of pulmonary rehabilitation to eligible patients, along with flexible program models that improve access and consider comorbid disease.

**Ethics:** The La Trobe University Faculty of Health Sciences Human Research Ethics Committee and the Alfred Health Human Research Ethics Committee approved this study. Informed consent was gained from all patients before data collection began.

**Competing interests:** None declared.

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**References**


