Adherence to pulmonary rehabilitation: A qualitative study

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Summary
Objectives: To explore the experiences of chronic obstructive pulmonary disease (COPD) patients invited to join a pulmonary rehabilitation (PR) programme. PR has been shown to be an effective non-pharmacological intervention; however uptake and completion of programmes is frequently low.
Design: Qualitative study using semi-structured interviews
Participants: Twenty COPD patients aged 45–85 years, referred for PR over a 2-year period.
Results: In this group of patients the influence of the referring doctor was the key factor in leading patients to take up an invitation to attend a PR programme. Patients responded positively to doctors who imparted enthusiasm for, and belief in, the benefits of the intervention. Once started, ongoing adherence to the programme was positively influenced by a sense of group support, and increased self-confidence. Lack of social support at home and overcoming the effort of living with COPD in order to attend were cited as negative influences on continued adherence.
Conclusions: This study has shown that the referring doctor plays a key role in the uptake of PR programmes. It suggests that a positive approach by doctors could increase the level of adherence to PR. Recognition and support in the area of social support for those living alone may also increase adherence. These simple, cost effective approaches may encourage more patients with COPD to participate in a therapeutic intervention which now has a strong evidence base.

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KEYWORDS
COPD; Adherence; Pulmonary rehabilitation; Qualitative study

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Introduction

Chronic obstructive pulmonary disease (COPD) is a chronic respiratory disease that constitutes a major health problem and is a leading cause of morbidity and mortality worldwide. In the UK it has become the third most common chronic illness and causes around 26,000 deaths per year. The British Thoracic Society estimates that some 600,000 people suffer from COPD and this number is increasing year by year.

As there is no cure for COPD, medical treatment is directed towards managing the disease and alleviating symptoms, primarily through drug therapy. A non-pharmacological intervention that has been found to be effective is pulmonary rehabilitation (PR). The aim of PR is to return the patient to independent functioning, reduce disability and improve quality of life. However, not all patients who have been referred for PR receive the intervention as intended. Patients may refuse to attend initially, or drop out before the end of a programme. In 1998, Singh et al. found that of 267 patients referred to PR, less than half (132) completed the course. Adherence rates reported in randomised controlled trials tend to be higher, but this may be due to the effect of entering a trial. Non-adherence rates in chronic disease treatment recommendations are generally thought to run at around 50%. There is little published evidence regarding the factors that lead to COPD patients’ non-adherence to PR. Young et al. used an interviewer administered questionnaire and suggested that non-adherers were more likely to be depressed, widowed or divorced, live alone, live in rented accommodation and be smokers. Further insight into patients’ views, moving beyond questionnaires, is essential to allow doctors to develop strategies aimed at improving adherence to an effective intervention.

The aim of this study was to explore the experiences of COPD patients who have been invited to attend a programme of PR, in order to gain some insight into the aspects that may influence adherence.

Method

Semi-structured interviews were used to collect data from people who had or had not attended a PR programme. A grounded theory methodology was chosen. This involved using a systematic approach to data collection and analysis to develop themes inductively from the collected data, allowing the interviewer to focus on emerging areas of interest.

Procedure

Ethical approval for the study was granted from the Southampton & South West Hampshire Local Research Ethics Committee prior to recruitment.

Participants

Potential participants were COPD patients who had been invited to attend a hospital based PR programme over the previous two years. Exclusion criteria: patients who had dropped out due to hospital admission; patients who could not speak and understand English. Eligible patients were sent an introductory letter by a physiotherapist. Those not responding to the initial letter were sent a follow-up letter two weeks later. Those wishing to participate contacted the researcher and a convenient date was arranged to interview them in their own homes. Participants continued to be recruited until no new themes relating to the research question emerged from the data. Forty-six patients were invited to participate in total, 22 of whom made no response (despite a repeat letter), 21 replied expressing interest, three replied negatively and 20 agreed to be interviewed.

Data collection

The interview schedule included wide ranging open questions as well as probing questions, such as why they had initially decided to attend or not attend a programme of PR, and why they had decided to continue with PR or drop out before the end. Interviews were carried out by one of the authors (LA) and audio-taped with the consent of the participant. As the study continued and areas of interest emerged from the data, additional questions were included. Field notes were made immediately after each interview.

Data analysis

Within qualitative research the aim is to describe people’s experiences in great depth and within context, so that others can judge how applicable the findings are to their own situation. Each interview was transcribed in full including both participant and researcher contributions in order to allow an in-depth exploration. Each transcript was read and re-read several times to familiarise the
researcher with the data. Then a detailed analysis took place by coding, line by line, the experiences described in the data. Having coded each of the transcripts, these experiences were grouped into categories in order to make the data more manageable and highlight patterns in the data for each interview. Several transcripts were reviewed by one of the co-authors to highlight any alternative interpretations which could be included in the analysis. The categories identified for each interview were then compared and contrasted across all of the interviews so that the range of experiences could be explored. The categories reported in the analysis section are those which were shared generally by the participants which appeared relevant to the research question. Variations in experiences identified for one or two participants are also described to demonstrate alternative experiences within the same context.

Results

Of the 20 people who agreed to be interviewed, 16 had attended and completed a PR programme, 2 had never attended and 2 had dropped out during the programme. Five of those completing the programme had missed one or two sessions out of the 14 available. Of the 24 people who did not agree to be interviewed 12 had attended and completed a PR programme and 14 had never attended. This means that we were predominantly able to explore patients’ reasons for initiating and adhering to PR. Table 1 provides the demographic information about the study participants. Nine men and 11 women who had been referred for PR were interviewed. They were aged between 45 and 85 (mean 67) years and all had a diagnosis of COPD. Nine lived alone, 11 lived with a spouse or partner and all but three were retired. They had a range of COPD severity, as assessed by oxygen use and ability to leave the house. The only information known about the study non-participants is their postcode (i.e. the geographical area in which they lived). Figure 1 gives a pie-chart of postcodes comparing those who agreed to participate with those who declined/made no response. The general hospital at which the programme was based is in postcode SO17. Adjacent numbers relate to contiguous geographical zones, while higher numbers relate to more distant zones, but all are within 10 miles of the PR venue. The postcode areas within the pie-charts contain people with a broad range of socioeconomic characteristics. There were no discernible differences in postcode

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*Missed two sessions.
†Missed one session.
between those who agreed or declined to participate in the study.

The findings will be described in two sections: (1) experiences of adherence (both initial take-up and sustained adherence to PR), (2) experiences of non-adherence (defined as not starting PR or leaving during the programme). The figures in brackets after quotes represent participant number and line number.

Experience of adherence to PR

The following four key themes emerged from those taking up and completing a PR programme.

Positive influence of the referring medical practitioner

All but one of the participants who agreed to attend PR were referred by a respiratory consultant from a COPD clinic. The referrer had a significant effect on most of the participants in this study, who said they attended PR specifically because their doctor had suggested it was a good idea:

because X (consultant) advised it and I go on advice from somebody I think should know what they are talking about (19; 99)

because if people in those positions make suggestions then I listen to them because I have no medical knowledge (20; 124)

Some reported that the consultant had given them some information on why they were being referred, implying participants may have decided to attend the course because of the apparent expertise of their referrer:

she said it would be half-exercising and then talks about it and it might improve your general health which would help your breathing (19; 87)

Patients with COPD often have long-standing relationships with their doctors, developing significant trust in their medical knowledge and opinion. None of these participants had prior knowledge of PR, or received any information about the programme from other sources, so those who believed PR would be beneficial presumably gained this from their referrer.

Self-help

Some of the participants described how they wanted to help themselves and be active partners in the management of their condition. The following quote reflects this view:

giving me the opportunity to help myself and do something positive instead of just taking this, taking that (14; 193)

These participants saw PR as a valuable opportunity to take some control of their condition.

Enjoying the programme, seeing an improvement

Once participants had started PR, many described how much they enjoyed going to the programme:

once I’d gone once I wouldn’t have missed it for anything (14; 201)

This enjoyment stemmed from many aspects such as the activity itself:

I enjoyed going there because I liked the exercise (18; 171)

increase in confidence:

it made me feel so good that I was achieving so much (3; 160)

and improved self-esteem and mood:

I think psychologically I got really low without realising it…it [PR] was a real turning point…

![Pie charts of postcodes of study participants versus non-participants. Study participants (n = 20); study non-participants (n = 26).](image-url)
improved 100% in being able to get around (15; 54/152/213)

Enjoyment of any activity is a powerful motivator for its continuance. For these participants enjoyment and perceived improvement were closely linked and many felt that it played a significant role in their continued adherence to PR.

The effect of the group
On this programme, patients began and finished as a group, giving them time to get to know each other. Many participants talked about the effect of the group on them as individuals.

Some said that until they went to the programme, they had never met anyone else with COPD:

up until then I hadn’t met anyone else with it (20; 144)
you think you’re the only one (2; 139)

For some participants, just being with other group members had encouraged them to do more:

you think if other people can do it so can I, it encourages you (2; 155)

Thus, providing treatment in a group environment was not only cost-effective, but also provided additional benefits to group members.

Experience of non-adherence to PR
The following two themes emerged from those who had either dropped out of, or not started, a PR programme.

Negative influence of the referring medical practitioner
Out of the two participants who had refused PR, one did not know the medical referrer, and the other had received the impression from their doctor that:

this may or may not help you (9; 109)

As mentioned previously the medical practitioner has a key role to play in this initial decision. One participant described how he felt he could prioritise other events:

when the dates came through we were going on holiday and that was more important (9; 124)

He was subsequently sent an invitation for an alternative programme had had already made previous plans:

I would do it but not on Fridays ’ cause I go to a community course (9; 127).
It’s (i.e. the community course) great, we really enjoy it so I’m not going to miss that (9; 231)

The other participant described how he felt much better in the summer months, and when the invitation arrived the programme was due to run during the summer:

I thought that’s going to take two days out of my weeks in the summer- I’m not doing that (8; 111/112)

Unfortunately, this participant had not discussed this with his doctor and was not offered any alternative dates.

Social support and motivation
Once the programme had started, two participants dropped out of PR completely, while five others missed occasional sessions. Many participants said they felt socially isolated by their condition and had viewed the programme as a means to get out and meet people. Of the two who had completely dropped out of PR, one lived alone and said she had originally gone to the programme because:

I don’t have many friends so I did use it as a bit of social time (11; 171),

but that she had dropped out because:

being on my own there is no-one to give me a bit of a push or encouragement (11; 176).

The other suggested that he originally attended the programme because:

If you’re on your own and you go along to these things and enrol with other people, at least it gets you out of the house (18; 133)

He did not give a specific reason for dropping out except that he had:

felt bad (18; 177).

However, he added that he was alone all day and that he found this quite distressing at times:

for most people if there’s someone around it gives them a little more confidence (18; 82)

Both implied that it was because they were on their own that they found it difficult to motivate themselves to attend the programme. This lack of support is well documented as a reason for non adherence to an exercise programme, particularly in the elderly.13 Both of these participants were over 65 years of age.
Several participants who had missed one or two sessions suggested that the problems of just coping with their condition was as much as they could manage some days, and that going to PR was sometimes just too much for them:

most of my days are like that, get up and feel I can’t be bothered (2; 200)

and:

I just felt I couldn’t go (6; 164)

These participants lived alone. The fact that they did not drop out altogether, implies that they saw some personal benefit in continuing with the programme.

Although other issues, such as transport and parking difficulties were often mentioned by participants, none suggested these issues directly affected their adherence.

Discussion

The most frequently cited influence encouraging initial attendance at PR was the effect of the referring doctor. All the adherent participants reported having good relationships with their consultants, whose opinions they respected. It is known that doctors hold powerful positions in the eyes of COPD patients, who often want to be seen in a good light by them. Nordgren and Fridlund found that patients who had confidence in their referrer were more likely to have confidence in any healthcare recommendation. Barber et al. reported physician support to be a significant factor in patient adherence to cardiac rehabilitation. The adherent participants in this study may have attended the programme not only because their consultant suggested it, but also because they wanted to please someone they were likely to see frequently, given the chronic nature of their disease. This study demonstrates the significant impact of the enthusiasm of the referring doctor on patients’ initial take-up of PR.

Several studies have suggested that if patients cannot perceive the benefit of an intervention they will be less likely to adhere. This study has revealed that if the referring practitioner lacks enthusiasm or is not known to them, patients feel they can prioritise other events over PR. Referrers need to be aware of the benefits of PR and impart these to their patients, while showing awareness that competing events may affect people’s prioritisation of the programme.

Another key factor encouraging initial attendance was the desire for self-help. This finding reflects those of Zimmerman et al., who found that many patients offered a programme on COPD management said they wanted to attend because they believed attending would help them with their disease. Scharloo et al. have suggested that COPD patients who have active coping skills and believe in the controllability of their disease have significantly better functioning and adherence. Selecting only such patients for PR would probably improve adherence rates, but might also unfairly penalise those who are already struggling with their condition.

The factor that was most likely to encourage continued adherence to PR was enjoyment of the programme. Patients with COPD are known to have a higher than average incidence of depression, and PR has been reported to have a positive effect on mood. Enjoyment and a sense of achievement were both common themes, which may have led to a greater sense of ‘self-efficacy’. Self-efficacy has consistently been shown to be not only a determinant of exercise adherence, but also an aspect that increases with exercise in patients with COPD. It has also been suggested that COPD patients with higher self-efficacy scores have lower mortality rates. The aspect of enjoyment, increased confidence and self-esteem could be emphasised by referrers, in addition to the physical benefits of attending PR.

The effect of social support on motivation was raised by many participants, both adherent and non-adherent. Many talked of feelings of isolation which is a theme previously identified by Young et al. Meeting other patients had a positive effect on the participants in this study. Fraser and Spink reported that not only the social support provided by the group, but also the cohesion shown by the group, were important determinants of adherence to a prescribed exercise programme. This study has also highlighted the extreme effort required by some patients to allow them to attend PR, especially those who are house-bound or live alone. Additional support may be needed to enable such patients to complete a programme.

Limitations of this study

These findings need to be seen within the context of COPD patients attending a hospital based PR programme running twice weekly for seven weeks in the south of England. The participants included both genders, those living alone or accompanied, with a diverse range of age, level of disability and socioeconomic background. As the interviews were
retrospective it may have been difficult for some participants to recall exactly why they had made a particular decision at the time, however all participants spoke of the effect of the referring practitioner without prompting. Also, the majority of participants had completed a programme, which may have resulted in an incomplete or biased picture. The researcher collecting data had clinical experience of PR programmes which may have influenced the data. However, the analysis was systematic and included others who ensured that alternative interpretations and explanations were explored. Although this is a small study, we feel that we have identified an important aspect of adherence to PR programmes i.e. the role of the referring doctor in promoting initial take-up of the programme. This should have relevance to any doctors referring patients to PR programmes in the UK.

Future research

The referring doctor was found to have a major role in influencing the uptake of PR. Using this and other findings, it should be possible to develop a strategic package aimed at helping referring doctors to promote adherence. Future research could then test the effectiveness of such development against the standard.

Conclusion

PR is recognised as an effective non-pharmacological intervention for patients with COPD. However, the benefits hinge on the patient adhering to a programme, as adherence and outcome are totally interdependent. This study has shown that the referring doctor plays a key role in this process, and that it may be possible to increase the rate of uptake and adherence to PR programmes by changing medical practice in a way not likely to be time consuming. Recognition and support in the area of social support for those living alone may also increase adherence. These simple, cost-effective approaches may encourage more patients with COPD to participate in a therapeutic intervention which now has a strong evidence base.

References

Adherence to pulmonary rehabilitation