Hogg et al: Maintaining an active lifestyle following pulmonary rehabilitation

Introduction

Participation in regular physical activity is recognised as one of the most important health behaviours for reducing the impact of many chronic diseases (Schutzer and Graves 2004). The benefits of physical activity have long been recognised in cardiovascular disease, diabetes, musculoskeletal health, and mental illness (Department of Health 2004a). Physical activity may have a prognostic benefit for people with chronic obstructive pulmonary disease (COPD), having been associated with lower risk of mortality and of hospitalisation for COPD exacerbation (Garcia-Aymerich et al 2006).

Physical activity may seem counterintuitive for people with COPD because of associated exertional dyspnoea. Reduced activity can contribute to a downward disease spiral of worsening breathlessness, muscle de-conditioning, and disability (Polkey and Moxham 2006). Pulmonary rehabilitation aims to attack this spiral and has proven consistently effective for improving exercise tolerance and health-related quality of life in people with COPD (Lacasse et al 2006). A course of pulmonary rehabilitation typically comprises twice-weekly supervised sessions of exercise and education over six to eight weeks (BTS 2001). Despite unequivocal short-term effectiveness, the benefits tend to be lost at 12 to 18 months.

Maintaining the benefits of pulmonary rehabilitation is recognised as an important component of long-term disease management, yet uncertainty remains as to how this can be achieved. A paucity of compelling evidence exists

Question: What are the views and perceptions of people with chronic obstructive pulmonary disease (COPD) regarding maintaining an active lifestyle following a course of pulmonary rehabilitation? Design: Qualitative study of two focus groups using a grounded theory approach. Participants: Sixteen people with COPD who had completed a course of pulmonary rehabilitation. Results: Data from focus groups concurred and five main themes emerged: value of pulmonary rehabilitation, ongoing exercise, professional support, peer social support, and health status. Pulmonary rehabilitation was seen as facilitating greater participation in everyday activity by improving physical ability and confidence to manage breathlessness, and reducing fear about exertional activity. An exercise routine following rehabilitation was perceived as essential for maintaining activity, with participants voicing a need for ongoing, structured and supervised sessions to maintain newfound abilities. The exercise facility presented a possible barrier to attendance due to its potential to provoke feelings of embarrassment or intimidation. Professional and peer support were identified as key elements; participants expressed a desire to exercise within a peer group combined with an opportunity for social interaction. Health status relating to COPD symptoms was also identified as negatively impacting on physical activity participation. Confidence or self-efficacy for physical activity emerged as a prominent factor within main themes. Conclusion: The opportunity for structured, ongoing exercise with peer and professional support, in a suitable venue, is perceived as important to people with COPD in facilitating a physically active lifestyle following pulmonary rehabilitation. This desire for such opportunities may be related to individuals’ self-efficacy towards physical activity. [Hogg L, Grant A, Garrod R, Fiddler H (2012) People with COPD perceive ongoing, structured and socially supportive exercise opportunities to be important for maintaining an active lifestyle following pulmonary rehabilitation: a qualitative study. Journal of Physiotherapy 58: 189–195]

Key words: Chronic obstructive pulmonary disease, Pulmonary rehabilitation, Physical activity, Maintenance, Qualitative research

What is already known on this topic: Pulmonary rehabilitation improves exercise tolerance and quality of life in people with chronic obstructive pulmonary disease. Ongoing adherence to exercise appears important to maintain the benefits of pulmonary rehabilitation, but it is unclear how adherence can be supported.

What this study adds: People with chronic obstructive pulmonary disease who have completed a course of pulmonary rehabilitation believe that ongoing structured exercise with professional and peer support would assist them to continue regular exercise. They also believe that their health status could limit their exercise adherence. These factors may influence engagement in physical activity by modifying confidence to exercise.
supporting supervised maintenance initiatives (Ries et al 2007) with a recent study demonstrating no additional benefit of weekly, supervised exercise classes compared to unsupervised exercise alone (Spencer et al 2010). Yet anecdotally researchers consistently encounter patients who, upon completion of pulmonary rehabilitation, voice a desire for continuation of structured supervised sessions that are similar in format. This prompted interest in the patients’ perspectives of continuing with regular physical activity following pulmonary rehabilitation.

Since physical activity is a complex behaviour (van Sluijs et al 2007), insight into the patient’s unique viewpoint is warranted in order to enhance understanding of how people with COPD might maintain benefits of pulmonary rehabilitation and continue with an active lifestyle. Qualitative research conducted in the field of pulmonary rehabilitation has focused on patients’ immediate experiences and perspectives of undergoing a course of pulmonary rehabilitation; specifically the education component (Wilson et al 2007), the impact of pulmonary rehabilitation on the experience of living with COPD (Toms and Harrison 2002), and on perceptions of breathlessness and activity (Williams et al 2010). Across these small studies pulmonary rehabilitation was universally perceived to be highly valuable for improving coping abilities and physical and psychosocial function. Follow-up activities were seen to be important (Toms and Harrison 2002, Wilson et al 2007) but exploration of attitudes and experiences following a course of pulmonary rehabilitation was not the primary concern of this research.

At the outset of this study, the authors were unaware of any published work focusing on the views of people with COPD towards physical activity after pulmonary rehabilitation. Consideration of this subject from the patient perspective reflected key drivers of UK and worldwide health policy to consider patient opinion in evaluation and evolution of health and wellbeing services (Department of Health 2004b, IAPO 2009). The following research question was formulated:

What are the views and perceptions of people with COPD towards maintaining an active lifestyle following a course of pulmonary rehabilitation?

**Method**

**Design**

A qualitative focus group design was selected because group interaction can prompt responses that might not be elicited during interviews, leading to a deeper level of inquiry. The group setting offers a supportive environment in which participants can express their views and is familiar to people who have completed a course of pulmonary rehabilitation. Two focus groups were held at a community hospital. The principal researcher (LH), a respiratory physiotherapist, took the role of moderator. An independent physiotherapist (AG) observed and took notes on participants’ non-verbal communication, group interaction and key ideas (Holloway and Wheeler 2002). Focus groups were digitally audio-recorded and transcribed verbatim. Group discussion was facilitated using a topic guide of eight open-ended questions that had been developed with an experienced researcher (HF) (Box 1). All questions were piloted with a group of physiotherapists and standardised in order to enable comparability across both groups. All participants provided written, informed consent.

**Participants**

Purposeful sampling was employed (Ritchie et al 2003). Inclusion criteria were COPD diagnosis (GOLD 2005), completion of an 8-week outpatient pulmonary rehabilitation course held either in a hospital gym or in one of four community venues within the last two years, and ability to access the pulmonary rehabilitation venue independently. Exclusion criteria were no spoken English or requirement for transport provided by the hospital.

We set out to include people with a range of experiences in relation to pulmonary rehabilitation to generate rich data and to introduce diversity whilst maintaining overall homogeneity (Finch and Lewis 2003). Using records held by the pulmonary rehabilitation team, eligible participants were placed into two groups, A and B, by the principal researcher. Group A had received input from pulmonary rehabilitation staff to assist with ongoing exercise following completion of the pulmonary rehabilitation course, either by choosing to attend a maintenance gym session run by pulmonary rehabilitation staff or by receiving an induction into an existing community class from pulmonary rehabilitation staff. Group B had not received any input from pulmonary rehabilitation staff regarding ongoing exercise due either to choice or lack of opportunity for pulmonary rehabilitation staff to support their chosen exercise option. Suitable patients were approached via letter. Recruitment continued until nine positive responses had been received from each group, in an attempt to secure six to eight participants per group.

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**Box 1. Topic guide used to facilitate focus groups.**

**Introductory Question:** Tell me about your experience of the pulmonary rehabilitation course.

1. Tell me how you felt when you finished your course of Pulmonary Rehabilitation.
2. Tell me about any kind of physical activity or exercise you have done, or still do, since you finished Pulmonary Rehabilitation.
3. Have you found any differences in how physically active you are since you finished Pulmonary Rehabilitation compared with when you were on the course?
4. What helps you, or would help you, to stay active?
5. Is there anything that makes it difficult for you to stay physically active when you have COPD?
6. Tell me about anything that has been important in helping you to stay active since finishing Pulmonary Rehabilitation.
7. Looking back, is there anything you could suggest that could have been done differently during the Pulmonary Rehab course that would have helped you to be more active outside of the classes and after the course?
8. What do you feel is the most important thing in helping you to stay physically active when you have COPD?
Data analysis

Data were analysed manually using a grounded theory approach (Charmaz 2006). Each segment of transcribed data from Group A and B was coded openly. Frequently occurring codes were used to re-organise and integrate the data into broader categories and themes, and inter-theme relationships were identified. Mind-maps facilitated this iterative process (Braun and Clarke 2006).

An experienced qualitative researcher (HF) reviewed the coding process to enhance analysis credibility. The observer (AG) reviewed the findings independently and concurred with the themes identified. Respondent validation was carried out by two participants in each focus group, who agreed that the analysis accurately reflected their discussion. To guard against a selective narrative, the researcher purposely chose individuals who, between them, embodied a range of views within the dataset (O’Neill Green et al 2010). The results were reviewed by two expert pulmonary rehabilitation practitioners, who confirmed that the findings were meaningful and credible in relation to personal experience. A critically reflexive account and audit trail were maintained throughout to establish dependability and confirmability (Holloway and Wheeler 2002).

Results

Participants

Of the 28 people approached by letter, 22 responded initially to express interest and 16 participated in the focus groups. Two people were unable to participate due to hospital appointments, one person was unwell on the day of data collection, and two were unable to be contacted by telephone to arrange attendance. Demographics of those in Group A (n = 9) and Group B (n = 7) are summarised in Table 1.

Themes

Five main themes were identified within focus group data from both Group A and B and are shown in Box 2. The themes and subthemes were consistent between groups and are presented in Box 2, with example statements from participants to illustrate the theme. Additional participant statements are provided in Appendix 1 to further justify the themes and subthemes (see the eAddenda for Appendix 1).

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<th>Data analysis</th>
<th>Box 2. Themes and subthemes among participants’ beliefs about maintenance of activity after pulmonary rehabilitation.</th>
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**Value of pulmonary rehabilitation**

Pulmonary rehabilitation was viewed as highly beneficial by participants, having experienced for themselves the positive impact of regular exercise on their daily lives.

*I got up those stairs without collapsing at the top and feeling so out of breath. That’s when I realised … it was working, it was going to help me to get around more comfortably … so that encouraged me more to do the exercises.*

(Group B, participant 3)

**Education and knowledge**

Improved knowledge and understanding of symptom management facilitated greater control over breathlessness. Enhanced understanding of the benefits of regular activity as part of disease management prompted increased participation.

*[I learnt] how to stand and get your breath back. I do that now if I get really breathless … I used to panic before and now I do that and it helps.*

(Group A, participant 6)
It makes you more aware; rather than jumping on a bus, I’ll walk down the road.

(Group B, participant 6)

**Confidence to be active:** Pulmonary rehabilitation reduced fear and anxiety associated with exertional activity, enabling and motivating participants to do more than they would otherwise have done. The experience of exerting themselves in the pulmonary rehabilitation class without ill effect boosted their confidence – or self-efficacy – to be more active.

*Before I did pulmonary rehab, if I wanted to go out, I would think no … maybe I won’t go because I’m feeling a bit breathless today but [now] I don’t have to worry about going places that I want to go.*

(Group A, participant 3)

*I amazed myself what I could do … I now know that I can do a lot more safely than what I thought I could do before.*

(Group B, participant 7)

**Ongoing exercise**

Participants in both groups were keen to maintain their newfound level of ability and expressed a desire for continuation of pulmonary rehabilitation.

*Putting in a nutshell, this is what we’re all talking about, we would like the classes to carry on.*

(Group A, participant 1)

*I felt so much better that I didn’t want it to stop.*

(Group A, participant 3)

When regular exercise ceased, either through temporary inability to attend maintenance in Group A or following pulmonary rehabilitation in Group B, deterioration in physical ability and symptoms was commonly experienced. The confidence and motivation to be physically active initially gained during the course tended to diminish thereafter.

*I was forever getting on buses, but after four weeks going to pulmonary class, I was walking there! I would have put money on it that I wouldn’t have been able to do it … then after packing up, the buses looked attractive. Psychological I think, you’re not doing it no more, puff puff!*

(Group B, participant 1)

**Routine:** Regular exercise was viewed as essential for enabling an active lifestyle with routine of time and place facilitating participation. Motivation to exercise at home was lacking for most, regardless of supportive tools available such as an exercise diary or DVD.

*I certainly wouldn’t do any exercises at home. I’m dead idle in that respect, it’s not a question really of time, it’s just difficult to get the motivation to do it at home so making myself go to the gym [maintenance session] once a week, at least I know that for that time I’m there, I’m doing all sorts of things which are helping me.*

(Group A, participant 7)

**Exercise facility:** The venue available for exercise was seen as a potential barrier to attendance. Several participants in Group B had not persisted with exercise at facilities suggested to them on completion of pulmonary rehabilitation, predominantly because they felt discontented by the environment and the fitter, healthier clientele referred to as ‘Popeyes or Prima Donnas’.

*The reason [I didn’t go] was because I looked in the gym and saw all this elaborate technical equipment … and the people who were using it. They go there to do their stuff. And if you don’t do your stuff, you’re standing out like a sore thumb.*

(Group B, participant 5)

In contrast, many participants in Group A had accepted the opportunity to attend a maintenance session run in a public gym by pulmonary rehabilitation staff. They exercised alongside members of the public but under supervision and amongst fellow graduates from other local pulmonary rehabilitation courses. Initial feelings of intimidation and embarrassment were eased by the staff and peer group facilitating the transition.

*The first time I went, oh god, the noise … youngsters on the machine next door pounding away, and I thought for god’s sake, let me out of here! Now, I have a different attitude, I’ve got to know the staff, I’ve got to know some people there.*

(Group A, participant 2)

Similarly, participants in Group B were keen to attend a public facility if they could exercise alongside people with similar conditions. Some indicated a preference for a gym setting, others for a class environment but having access to a range of suitable and accessible community facilities was important.

*I [would] quite like to have a go on the machines … provided the blokes with buttocks like bricks are not hanging around … It would be on a day when these people weren’t there. There would be lots of people like us.*

(Group B, participant 4)

**Professional support**

Staff encouragement and conviviality were highly regarded, exerting motivational influence within both pulmonary rehabilitation and maintenance exercise settings.

*You might for the first few weeks think I’ll do this, I’ll try that, but gradually … it slacks off and you do less. I think because you haven’t got the encouragement there.*

(Group B, participant 6)

**Confidence:** In light of chronic and fluctuating medical problems, access to advice and reassurance from skilled
staff was particularly valuable for enhancing confidence to exercise.

When you've got a fairly serious medical condition, it's very reassuring to have medical people there because they can advise, help you and so on.

(Group A, participant 2)

Familiarity with staff helped to ease anxiety associated with moving to a new venue. Supervision, albeit in a less intensive form than during pulmonary rehabilitation, was important for guiding components of the exercise programme for which participants lacked confidence – such as the cool-down – or for altering or progressing regimens. Ongoing encouragement was important for maintaining participants’ confidence that they could safely exert themselves beyond usual limits.

They give you confidence … to push yourself a bit, to try to do a bit more.

(Group A, participant 8)

**Peer social support**

**Fellowship**: Participants greatly valued the peer support found within pulmonary rehabilitation. Camaraderie contributed to a sense of enjoyment, which positively influenced attendance and physical effort exerted during the classes. The sociability encountered at pulmonary rehabilitation commonly provoked feelings of sadness when leaving the course. Despite attending ongoing exercise sessions supported by the pulmonary rehabilitation team, many participants in Group A expressed regret that pulmonary rehabilitation could not continue in its original form, largely due to the established social network.

I didn't really want to go anywhere else because we got used to the place, the people, it was like a little circle, family if you like and made quite a lot of friends. And then it suddenly stopped. And we had to consider going somewhere else … I was really upset at finishing … it was a sort of emotional thing as well as a physical thing.

(Group A, participant 2)

You got someone, somewhere to look forward to going … We had a fantastic repartee there between the lot of us.

(Group B, participant 1)

Sharing experiences of living with COPD and the opportunity for social interaction was seen to be an important aspect of both pulmonary rehabilitation and ongoing exercise options. The feeling of belonging to a group facilitated regular attendance at maintenance sessions.

The people that I know at the gym, we've all done pulmonary rehab and we all have a cup of tea after we exercise together and that encourages me to go, cos I think 'Ooh if I don't go today ... they'll wonder where I am'.

(Group A, participant 3)

**Confidence**: Social support from a disease-specific peer group helped to reduce feelings of isolation that can accompany a chronic disease. A sense of security was gained from exercising alongside others with similar symptoms, reducing feelings of self-pity and self-doubt.

If you're mixed with other people with the same complaints, same problems ... you have a lot more confidence.

(Group A, participant 6)

**Health status**

Symptoms relating to COPD were commonly cited as a significant barrier to participation in physical activity. Breathlessness predominated due to its imposed physical restriction and associated psychological and emotional effects including feelings of embarrassment and defeat.

If you can't breathe properly, it's very hard to do anything ... You're inclined to think, 'Oh I can't do it,' so I don't do it.

(Group A, participant 2)

Variability and unpredictability of symptoms were identified as factors that could influence activity, as were energy levels, mood and chest infections.

Levels of activity go up and down, my lungs do not stay the same all the time ... you can't just say this regimen is going to work, because in three weeks, three hours, your breathing could be completely different.

(Group A, participant 3)

The routine and peer support of structured exercise sessions were helpful for motivating participants to overcome some of the barriers to activity imposed by chronic ill health.

There's a time in the week when you're going to be there so it doesn't matter what you feel like, you're going to do it ... You're gonna go there, so you've got motivation.

(Group B, participant 7)

**Discussion**

Our findings suggest that people with COPD perceive peer and professional exercise-focused support to be important for maintaining an active lifestyle after pulmonary rehabilitation. This complements previous qualitative studies where a need for ongoing but less comprehensive rehabilitation has been articulated (Toms and Harrison 2002, Wilson et al 2007). The importance of routine and social reinforcement within the exercise setting is also supported by previous research in general populations (Dishman et al 1985). While our study was in progress, Lewis and Cramp (2010) published their qualitative exploration of facilitators and barriers to exercise maintenance amongst six pulmonary rehabilitation graduates, identifying comparable themes of peer and professional encouragement, health status and environment. Adding to these findings, our study sampled a larger group and aimed to explore more deeply the rationale underpinning identified factors.
Confidence featured within several themes in the current study. Participants identified pulmonary rehabilitation as instrumental in enhancing physical activity participation by improving confidence to manage breathlessness and reducing fear of activity, reflecting the findings of Williams and colleagues (2010). Potential difficulties with continued activity were believed to be surmountable given access to structured exercise with social integration among peers and skilled staff. Our data suggest this desire for exercise opportunities after pulmonary rehabilitation is related to the confidence of individuals with COPD to continue with behaviours adopted during pulmonary rehabilitation.

Although ‘confidence’ is a nonspecific term referring to strength of belief, it is an important component within the construct of perceived self-efficacy – the belief in one’s ability to succeed in a specific situation (Bandura 1997). Low self-efficacy for coping with exertional breathlessness develops commonly in COPD (Wigal et al 1991). Our findings, and those of Williams and colleagues (2010), suggest pulmonary rehabilitation participation can redress this negative influence on physical activity. Bandura’s theoretical sources of personal efficacy – performance accomplishment, vicarious experience, verbal persuasion, and emotional arousal (Bandura 1977) – offer mechanisms through which pulmonary rehabilitation may influence self-efficacy for coping with exertional breathlessness and participating in physical activity. Loss of these sources on discharge from the course may negatively impact on self-efficacy, which arguably could diminish further during an exacerbation. Ongoing peer support for exercise was viewed as particularly influential in our study; a finding corroborated by research in older adults showing that exercise-focused social support promotes long-term adherence to exercise, mediated via self-efficacy (McAuley et al 2003). Our data also support the more specific theory that maintaining physical activity self-efficacy for people with COPD is important for sustained engagement in physical activity after pulmonary rehabilitation.

Various maintenance interventions have been tested in clinical trials as strategies are sought to effectively maintain pulmonary rehabilitation benefits longitudinally. Conclusions from this work so far are equivocal. Spencer and colleagues’ (2010) randomised trial demonstrated no additional benefit of once-weekly supervised maintenance over unsupervised home exercise. Interestingly, exercise capacity and quality of life were maintained one year after pulmonary rehabilitation in both strategies. Limitations of this well conducted study are worthy of consideration. First, regular contact with the pulmonary rehabilitation physiotherapist in the unsupervised group may have unduly biased adherence to long-term exercise. Second, it is possible that the study cohort was an atypical, highly functioning subgroup of people with COPD, with mean six-minute walk distances of 464 m and 527 m before and after pulmonary rehabilitation, respectively. This is substantially higher than the typical six-minute walk distance of 388 m in people with COPD (Casanova et al 2007). Distances around 500 m have been reported for healthy age-matched controls (Casanova et al 2011). Therefore, the generalisability of the results of Spencer et al (2010) is debatable.

The quantitative data showing that maintenance programmes have limited efficacy contrasts with patients’ perspectives expressed both in our study and in similar work (Lewis and Cramp, Toms and Harrison 2002, Wilson et al 2007). However, we acknowledge that our study did not include patient views concerning different modes of maintenance. Given the known health and economic benefits of regular physical activity in COPD (García-Aymerich et al 2006), further research is warranted to improve our understanding and potentially cost-effective activity promotion strategies for this population. For example, a trial could examine whether referral to independent group exercise sessions in a community hall with remote access to a pulmonary rehabilitation specialist promotes greater long-term participation in physical exercise than no ongoing support.

We acknowledge some limitations of our study. Theoretical sampling was lacking; further focus groups are required to achieve data saturation and to subsequently test the emerging theory with a larger and more diverse sample. Our attempt to control bias by recruiting individuals unfamiliar to the moderator was not wholly achieved (11/16, 69%) due to the moderator’s clinical role within service delivery. All participants were inner city inhabitants, mainly of white ethnicity and with moderate COPD, which limits the study’s generalisability somewhat. Also, the current study only reflects views of patients who were able to access pulmonary rehabilitation locations independently. Since inadequate transport is associated with some patients’ ability to participate in pulmonary rehabilitation (Keating et al 2011), the selection bias introduced by our inclusion criteria is a limitation.

These data highlight the difficulties experienced by people with COPD in maintaining an active lifestyle and suggest that confidence is an important determinant of physical activity participation in COPD. Health services should look to work in collaboration with local authorities and voluntary organisations to increase opportunities for people with COPD to be physically active, recognising the importance of continued peer and professional support.

Ethics: The Faculty of Health Research Ethics and Governance Committee, University of Brighton; Lewisham Local Research Ethics Committee, University Hospital Lewisham; and the Research and Development Committee of King’s College Hospital NHS Foundation Trust approved this study. All participants gave written informed consent prior to data collection.

Addenda: Appendix 1 available at jop.physiotherapy.asn.au

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