Factors affecting the offer of pulmonary rehabilitation to patients with chronic obstructive pulmonary disease by primary care professionals: a qualitative study

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Aim: To explore health professionals’ experiences of barriers and facilitators to referring patients for pulmonary rehabilitation in a primary care setting. Background: Pulmonary rehabilitation involves a multidisciplinary teamwork approach to improving the quality of life for people with chronic obstructive pulmonary disease. This study aimed to find out about health care professionals’ experiences when referring patients. Reports suggest that a health care professional’s attitude towards a treatment affects the willingness of patients to accept advice. Methods: Five focus group interviews were undertaken with 21 health professionals from North Midlands, UK. Data were analysed using a thematic analysis drawing on the techniques of grounded theory. Findings: Chronic disease management has been delegated to Practice Nurses in many cases leaving some nurses feeling unsupported and some General Practitioners feeling deskilled. Problems with communication, a lack of adequate and timely local service provision, a difficult referral process, time pressures and lack of information were barriers to health care professionals making an offer of pulmonary rehabilitation. An explanatory model is proposed to describe how addressing barriers to referral may improve health care professionals views about pulmonary rehabilitation and therefore may mean that they present it in a more positive manner.

Key words: attitude of health personnel; chronic obstructive pulmonary disease; communication barriers; professional–patient relations; pulmonary disease; qualitative research

Received: 6 May 2008; accepted: 9 July 2008; first published online: 11 September 2008

Introduction

Chronic obstructive pulmonary disease (COPD) is a chronic, slowly progressive disorder and was responsible for 107,352 hospital admissions and 30,634 deaths in the UK in 1999/2000. COPD accounts for more than £800 million in direct health care cost per year and is responsible for 1.4 million general practice consultations and one million in-patient bed days per year (CMO Annual Report 2004, 2005). Furthermore, COPD has a significant impact upon the lives of those who live with it and on those of their carers. Health care professionals have begun to recognise that good chronic disease management affords opportunities to improve patient care and cut down on health costs, a key element of which are rehabilitation programmes (DOH, 2004). This
Factors affecting the offer of pulmonary rehabilitation to patients with COPD

Background

Pulmonary rehabilitation programmes use multi-disciplinary teams to optimise physical and social functioning and health status in patients with COPD. In the context of COPD, this implies recognition of the partially reversible secondary systemic and psychological impairments of the illness. A pulmonary rehabilitation programme should aim at the following:

- To provide an individually tailored, multi-disciplinary intervention;
- To reduce symptoms, improve functional performance, increase participation and reduce health care costs;
- To contain an effective, individually prescribed, physical exercise training together with lifestyle and self-management advice;
- To address the social and psychological impacts of the disease on the patients and those close to them;
- To monitor progress with appropriate individual outcome measures and programme quality control (Impress, 2008).

The use of pulmonary rehabilitation has been supported by a Cochrane review (Lacasse et al., 2006) and recommended by the National Institute for Health and Clinical Excellence (NICE, 2004). Pulmonary rehabilitation is usually recommended for patients with COPD who have noticeable disability (Medical Research Council (MRC) breathlessness rating 3–5, Bestall et al., 1999), but excludes those with significant co-morbidities such as stroke, dementia, unstable angina or severe arthritis. It has been shown to improve quality of life and functioning for patients, reduce hospital admissions and in-patient stay with exacerbations of COPD (Arnold et al., 2006) and has been proven to be cost effective (Griffiths et al., 2001). Pulmonary rehabilitation is however a scare resource, with only 2% of those who needed the service gaining access to it (CMO Annual Report 2004, 2005). It is therefore important to maximise the appropriate use of the service where it exists.

Furthermore, there is evidence that patients may be reluctant to accept the opportunity to undertake rehabilitation, with studies reporting uptake rates of only 33–39% by those offered it in an out-patient setting (Bendstrup et al., 1997; Young et al., 1999; Garrod et al., 2006). A number of factors may be responsible for the poor level of acceptance; one may be the effect of attitudes of the referring doctor to pulmonary rehabilitation on the patient’s willingness to accept the offer of pulmonary rehabilitation. The effect of physician’s attitudes on patient satisfaction and the outcome of treatment have previously been reported in other aspects of patient care (Thomas, 1997; Topacoglu et al., 2004; Thapar and Roland, 2005). This study, therefore, aimed to explore health care professionals’ experiences when trying to refer patients for pulmonary rehabilitation and to see whether these experiences affected their attitude towards pulmonary rehabilitation.

Aims

In this paper, we sought to understand health professionals’ experiences of referring patients for pulmonary rehabilitation and to understand the barriers and facilitators health professionals face when offering pulmonary rehabilitation. The research question informing this study was: What factors affect the offer of pulmonary rehabilitation to patients with COPD by health care professionals?

Methodology

Given the exploratory nature of the research question, a qualitative research approach was utilised. Qualitative methods aim to explore a range of views and experiences, and the factors and circumstances that shape and influence them. The value of qualitative methods lies in their ability to pursue systematically the type of research questions not easily answered using quantitative methods. There are a wide range of theoretical frameworks, methodologies and methods that can be used in qualitative approaches to research. This study utilises a grounded theory approach to the collection and analysis of data and uses these methods to present a conceptual map of factors that affect the offering of pulmonary rehabilitation.
Data collection

Informal discussions were undertaken with health professionals outside the study group to identify the key subject areas for the focus group topic guide. The focus groups were facilitated by one researcher with health professionals, recorded and transcribed verbatim. Recordings were revisited following the sessions and key topics noted. Questions were amended in the light of ongoing data analysis and memoing.

Data analysis

Data collection and analysis occurred concurrently in a grounded theory style and used inductive reasoning – aiming to use information from each particular case to draw general conclusions. Open inductive coding through line-by-line reading of transcripts was undertaken (Barr et al., 2005; Jerant et al., 2005). To enhance rigour, two researchers checked a sample of transcripts for inter-coder verification. All participants were allowed an opportunity to convey their own meanings and interpretations through the explanations they provided. The health professional’s role is indicated when a quote is used. Primary codes from the data were derived by reading a quote and deciding the key message or concept a speaker was reporting. These codes were then placed in larger sub-themes that attempted to explain behaviours and were tested in subsequent focus groups. Finally, sub-themes were grouped together into key themes, which were used to develop a conceptual map to explain the behaviour. Respondent validation took place with two focus group participants, a GP and a Practice Nurse.

Findings

Results are presented using key themes and illustrative quotes with a unique identifier.

Changing roles of members of the health care team

In order to understand where barriers might occur in the pulmonary rehabilitation referral process, we used preliminary questions with focus groups to explore the roles of different members of the practice team in COPD management. This produced some interesting discussions about changing roles and ‘team working’. Health professionals
differed in the type of contact they had with patients who had COPD. Some Practice Nurses felt that chronic disease management was left to them. Team working was discussed, but it was apparent that some did not feel part of the team. GPs felt that showing a patient how to use inhalers, etc., was best done by the Practice Nurses: explained by GPs as ‘teamwork’. This often left Practice Nurses feeling irritated, and feeling that there should be more GP involvement in chronic disease management. Some respondents felt that GPs were not up-to-date with the latest developments. One Practice Nurse expressed her feeling that tasks were delegated without the appropriate provision of time to deal with them.

I think 100% has been handed over to the practice nurses, I personally don’t mind that. The doctors only seem to be involved if the patients got an exacerbation. They seem to get a bit uppity if somebody comes for a follow-up with them now……. I think it’s a bad thing because overall the GPs should have some input…they should have a little bit of the reins on the chronic disease management part of it.

(Senior Practice Nurse)

…GPs have not kept up with the inhalers and how they work… so we’re wasting money. I feel they should have more input into chronic disease management I think they need updating too.

(Practice Nurse)

…whether that’s time pressure or not, I don’t know, but we’ve got time pressures, we’ve only got 10 minutes too.

(Senior Practice Nurse)

GPs tended to deal with acute exacerbations and many admitted that the chronic disease management for patients with COPD had been delegated to Practice Nurses, leaving them feeling deskillled.

As a GP my contact with patients with COPD seems to be getting less and less. The times when I tend to see them are usually when there’s a crisis and therefore preventive type measures slip very low down in order of priority.

(GP)

…I sometimes worry about losing some of my (chronic disease management) skills, but I think I can manage the urgent part of it.

(GP)

However, in contrast to the comments by some Practice Nurses, GPs valued the expertise and skills that they felt their Practice Nurses/Nurse Practitioners possessed. GPs often explained this as ‘team working’.

If I’ve got any concerns about their (the patient’s) management I’ll send them in the nurse practitioner’s direction because they have a better understanding of what’s going on…. (patients are) better off being managed by somebody who sees it regularly than someone who intermittently deals with it.

(GP)

My ability to teach somebody to use an inhaler is not very good and there are other people who are far better at it than me so why not get them to do it?

(GP)

Communication

When considering patient referral for pulmonary rehabilitation, the importance of communication and the problems encountered when it failed were emphasised by all members of the practice team. For many, information sharing about pulmonary rehabilitation, whether it was between secondary (hospital) and primary care, within the Practice or between health professionals and patients constituted a barrier. A further barrier identified by a number of Practice Nurses was the confusion that many patients had with the diagnosis of COPD. Some reported that patients had previously been mislabelled or misdiagnosed as asthma rather than COPD. The low media profile of COPD, lack of appropriate patient information and awareness about COPD and pulmonary rehabilitation contributed to the difficulties Practice Nurses faced.

Patients with COPD need to understand that
COPD is different from asthma and that pulmonary rehabilitation may benefit them.

I don’t think we did label it in general practice as COPD, There’s a lot of misdiagnosis as asthma previously. If people have asthma, they sort of understand asthma, they don’t understand COPD.

(Practice Nurse)

Reps produce something (about COPD), but they’re really big, and don’t meet ‘The Sun’ reading age, they’re quite heavyweight stuff.

(Practice Nurse)

Patients don’t know about pulmonary rehabilitation, I’ve only ever been asked once by a patient about it.

(Practice Nurse)

… heart disease has been raised up in the media, whereas COPD hasn’t, I think that’s another barrier…

(Practice Nurse)

Interestingly, bearing in mind the comments made about the changing roles of the Practice Nurses and the reduction in the involvement of GPs in chronic disease management, a number of nurses reported that patients were more inclined to place emphasis on what a doctor had told them:

……however hard nurses try, if the doctors say it, it’s much more valid….

(Practice Nurse)

Failures in communication between secondary and primary care are illustrated by the fact that some health care professionals were unaware of what was involved in pulmonary rehabilitation, or that they could make a direct referral.

If we know what happens (in pulmonary rehabilitation) then we can sell it better.

(Practice Nurse)

…it’s not exactly clear who we can and can’t refer or even how to refer…….

(GP)

Logistics of referral for pulmonary rehabilitation

Health professionals told us about the barriers they encountered in offering pulmonary rehabilitation during the day-to-day running of their clinics. We have grouped these together under the theme of logistics. Lack of adequate local service provision for pulmonary rehabilitation was a barrier when making an offer, which discouraged health professionals from considering a referral.

…when I rang… it would be 6 months before the patient could go!

(Practice Nurse)

There’s a long waiting list for pulmonary rehab which makes you think, is it worth telling them about it?

(Community Matron)

Concerns were raised about the administrative burden of making a referral for pulmonary rehabilitation, and though a standard referral form does exist, even this was felt to be too involved.

…there’s too much information required… There’s a two sides of A4 form that they won’t accept unless we complete it.

(GP)

…it would certainly aid us if we didn’t have yet another bit of paper work that was sort of taking time out.

(GP)

…we’ve got to have it easy for us, because we’re human and at the end of a long day, if it’s one step too difficult, you feel you can’t do that today.

(Practice Nurse)

Solutions to some of the problems were volunteered, eg, patient self-referral was mentioned by Practice Nurses and ‘Practice Nurse referral’ by GPs. A local example of where self-referral had worked well was given:

…one of the reasons why the cardiac club in X has taken off so well and is so successful is that….patients can refer themselves. They go and join rather than being sent to it.

(GP)

The difficulty of making time for information giving during a normal consultation was frequently mentioned by all members of the health care team. Practice Nurses in particular recognised the benefits of protected time for information giving.
...the traditional timescale of a 10 minute consultation means that if you get round to talking about pulmonary rehab you’re doing very well and actually there doesn’t seem to be a role for it within the typical general practice model.

(GP)

It depends how much time you have with the patient, if you’re running late, you know, perhaps, other things suffer.

(Practice Nurse)

...people are more inclined to listen during a planned consultation (about their chest).

(Practice Nurse)

**Patient’s willingness to accept referral**

Health professionals recognise that patients need to be receptive to the offer of pulmonary rehabilitation and that some groundwork had to be done for this to take place. A number of elements that facilitated this were identified, such as empathy and developing a rapport with a patient:

We haven’t got COPD, so we sit there, obviously fitter than they are, offering them information about how to manage their lives.

(Practice Nurse)

...when people come back, and we’re getting on OK then I broach subjects like smoking.

(Practice Nurse)

Listening to patients and being receptive to the patient’s agenda was felt to be important by all as a way to understand patient’s barriers to pulmonary rehabilitation and to address them. Some health professionals were aware of behaviour change models and the importance of identifying the moment to make an offer of pulmonary rehabilitation or to encourage behaviour changes.

I don’t know that we’d always give then enough time to tell us things... we don’t spend enough time listening to what they’re saying to us so we might give appropriate advice.

(GP Registrar)

...you have to repeat yourself and identify their barriers and get over them to help them change.

(GP)

I think it’s all about identifying the moment, not just for us... but for them, when they feel it’s the right time.

(Practice Nurse)

...if they’re not ready to change, you can talk to them until you’re blue in the face and you’re wasting your time.

(Practice Nurse)

A variety of views were expressed about when it was best to make an offer of pulmonary rehabilitation. When patients came for unrelated problems (even if the health professional felt it was related), it was not felt to be a good time.

...for people who have a lot of acute exacerbations they want to change, and are more inclined to change.

(Practice Nurse)

...if they’re coming for a BP (blood pressure) they don’t want to listen to talking about their chest or smoking; you know, they don’t link it like we do.

(Practice Nurse)

Health care professionals correctly identified the key barriers to patients accepting the offer of pulmonary rehabilitation as previously reported in the literature, eg, fear of breathlessness and accepting or normalising their breathlessness (Barnett, 2005; Sassi-Dambron et al., 2005). These are obviously important because unless they are acknowledged and addressed the patient may not accept the offer of pulmonary rehabilitation, or may not attend.

I think patients are afraid of doing certain things, going on a walk when you’re breathless, that sort of thing.

(Practice Nurse)

I think a lot of patients feel that they can’t exercise, and that, you know, they’ve almost come to the end of the road... they are quite surprised when we suggest yes, yes you can (exercise).

(Community Matron)

Both GPs and Practice Nurses were aware of the ‘stigma’ that COPD might have for some patients, especially associated with its link to smoking. They recognised that this might be a
barrier to patient’s willingness to accept their diagnosis and appropriate treatment. Other factors such as patients’ lack of self-efficacy and nihilism were both mentioned too:

Perhaps because of the bit of self blame, and perhaps because they feel we’ll judge as well.

(Practice Nurse)

They would rather think its asthma and it’s not them to blame for it.

(Practice Nurse)

…it’s whether they want to accept responsibility for looking after their chest… a lot of them don’t.

(GP)

Patients whose feeling is one of despair…. I’ve got this, I can’t do anything about it, it’s just going to get worse….there’s nothing I can do really.

(GP)

Others emphasised the importance of ‘making pulmonary rehabilitation part of the treatment’ as patients were reported to place greater importance on medication as opposed to ‘lifestyle’ changes. Health care professionals recognised that patients had to feel that they would benefit in more ways than just their health.

It needs to be as much a part of the treatment as inhalers…this is an accepted part of treatment for COPD, you know, all the evidence is there to say it’s good, and it works really well, and we’ll be referring you

(Practice Nurse)

… patients are more willing to accept advice if they realise there’s a realistic goal….I think the social interaction is a reward and feeling better, and actually realising you can do it in a safe way…

(Practice Nurse)

Discussion

This study aimed to explore the factors that affect a health care professional’s willingness to make an offer of pulmonary rehabilitation to patients with COPD. It was interesting to discover the experiences and attitudes of health care professionals towards referring patients for pulmonary rehabilitation; in particular whether this might reflect the way in which health care professionals presented it to patients. Pulmonary rehabilitation has been shown to improve the quality of life and functioning of patients with COPD. The major limiting factor to referral for pulmonary rehabilitation is lack of adequate service provision, and as a consequence it is important to try and optimise its uptake.

The main barriers that health professionals faced when referring patients were lack of service capacity, long waits for patients to start pulmonary rehabilitation, paucity of patient-friendly information, lack of time and the perception of a difficult referral process. These themes were used to develop a model (Figure 1) to illustrate how health professionals’ attitudes might be affected by their views on pulmonary rehabilitation. Subsequently, it is proposed that lack of local service provision coupled with what is perceived to be a difficult or arduous referral procedure may mean that health professionals present pulmonary rehabilitation in a non-committal way despite some of them being aware of its benefits. Patients may therefore perceive pulmonary rehabilitation as less important and not ‘part of the treatment’. Health professionals may feel disempowered by the referral process and thus not consider the opportunity that pulmonary rehabilitation may afford when reviewing patients with COPD. If however there is adequate local provision and a streamlined referral procedure, making referral easier, then health professionals may be more likely to present pulmonary rehabilitation in a more positive manner, the outcome of which may be better uptake by patients.

The data demonstrated that the roles of members of the practice teams have changed, Practice Nurses, Nurse Practitioners and Community Matrons are delivering more chronic disease management. The main role of the GP appeared to be managing acute exacerbations, leaving some GPs feeling deskilled in chronic disease management. The key role for nurses in running chronic disease management clinics, with GPs taking on the responsibility for managing acute illness and complex chronic medical problems has, is reported by Blakeman et al. (2006). Some GPs frame this change as ‘team working’, ie, delegating chronic disease management to their Practice
Nurse colleagues. In contrast, a number of Practice Nurses and Health Care Assistants did not feel part of a team and expressed the need for more GP involvement, assuming the GP was up-to-date with current management. A discrepant attitude about teamwork between nurses and physicians has been reported in intensive care units where nurses felt that their voice was not heard, and that they wanted more input into decision-making (Thomas et al., 2003). Issues of multi-professional working have been raised in the provision of cardiac rehabilitation (O’Driscoll et al., 2007). The views of nurses about team working in the provision of chronic disease management indicating a feeling that they lack professional autonomy is reported by Wilson et al. (2006). Problems associated with nurses defining their role in multi-disciplinary teams have also been reported, with nurses feeling forced to act as substitute doctors and following a ‘medical model, rather than being innovators in care’ (Salvage, 2002). All of these factors will prevent effective team working.

It was noteworthy that some Practice Nurses felt that patients placed more importance on advice or instructions if they were delivered by ‘the doctor’. Stevenson et al. (2003) note that patients reported concerns as to whether (health care) professionals see self-care as legitimate. This statement resonates with the nurse’s observations about the need for affirmation by ‘the

Figure 1 The effect of barriers and facilitators to referral on health care professionals’ attitudes and their outcome on referral for pulmonary rehabilitation

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doctor’ or other health care professional whose opinion the patient values. It also reinforces the importance of a positive attitude about pulmonary rehabilitation by the referring health care professional.

The role of the Practice Nurse as a valued team member is important, as Practice Nurses are in a key position to offer pulmonary rehabilitation. For this to happen, Practice Nurses need to feel valued and appropriately supported as team members if they are to offer pulmonary rehabilitation to patients, rather than having yet another task delegated to them. Research on patient care provides evidence that improved team working results in better clinical outcomes and higher patient satisfaction (Grumbach and Bodenheimer, 2004).

Good communication by health care professionals within the practice and with secondary and primary care was felt to be important. A number of Practice Nurses reported difficulty in obtaining information about pulmonary rehabilitation and support from their colleagues in secondary care. Problems have previously been reported with communication between secondary and primary care, particularly in the provision of discharge summaries (Kripalani et al., 2007), and cancer care (Farquhar et al., 2005).

Lack of appropriate service provision for pulmonary rehabilitation was mentioned by our participants and is well recognised. The Department of Health estimates that only 2% of those who need pulmonary rehabilitation have access to it (CMO Annual Report 2004, 2005). Lack of service provision has also been reported as a barrier to referral for cardiac rehabilitation (Tod et al., 2002; O’Driscoll et al., 2007). Patient’s confusion about their diagnosis was reported here; there may be a number of explanations for this confusion such as a lack of information about their illness, which is frequently reported in the literature as a barrier to its management (Seamark et al., 2004; Barr et al., 2005). A further explanation may be the fact that asthma and COPD tended to be grouped together. Since 1 April 2003 and the development of the Quality and Outcome framework (General Practitioners’ Committee, 2003), new diagnoses of COPD should be confirmed by spirometry with a reversibility test to exclude asthma (although this is not infallible), which should help reduce further confusion. Misdiagnosis is an important barrier to referral of pulmonary rehabilitation, because if either patients or health care professionals do not have the correct diagnosis patients may miss the opportunity for appropriate referral for rehabilitation.

Health professionals identified factors that make patients more likely to change their behaviour including demonstrating empathy, recognising patient’s barriers to changing behaviours and the need for realistic goals and rewards. Respondents correctly identified patient barriers as fear of exercise or breathlessness (Barnett, 2005; Sassi-Dambron et al., 2005), self-blame, low expectations of themselves and their treatment (Morgan et al., 1983; McBride, 1994; Fischer et al., 2007). Recognition of the importance of the patient’s agenda, in particular how patients view themselves, is crucial when framing any offer of help (Jerant et al., 2005). The attitude of health professionals towards a service is important (Heszen-Klemens and Lapinska, 1984; Barr et al., 2005; Thapar and Roland, 2005). Charmaz (1997: 51) found that ‘when men believe in their doctors and their treatment, their resolve to struggle maintains their hope, giving a sense that the past self can be maintained if the doctor promises improvement in symptoms’.

**Strengths and limitations of the study**

Focus groups were undertaken with different health professionals providing an opportunity to explore a diversity of views. Participants are reported to feel more comfortable with others with whom they share similar characteristics; such groups are reported to facilitate disclosure of information. Using pre-existing groups allows triggering of memories and shared experiences (Kitzinger and Barbour, 1999). Health professionals’ attitudes towards pulmonary rehabilitation may influence the way they present it to patients, which may be a barrier for patients to using the service. There is an implied interaction and possible consequence, which makes grounded theory an appropriate methodology for this study. The role of the interviewer (a GP) may have affected respondents’ interaction. For example, they may have biased their responses, being more positive about pulmonary rehabilitation. This was addressed to some extent by explaining at the

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beginning of the focus groups that all views were equally valid. Using researchers from different professional and academic backgrounds to analyse the data is a recognised technique for increasing the trustworthiness of the analysis (Henwood and Pidgeon, 1992).

Conclusion

In this study, we propose that better communication between all health care professionals, improving local service provision and tackling the perceived logistical barriers for referral to pulmonary rehabilitation would improve health care professionals’ attitudes towards pulmonary rehabilitation. Better local service provision and streamlined referral pathways may lead to referrers presenting rehabilitation to patients in a more positive light. Improved team working between health professionals and greater emphasis on the role of Practice Nurses in offering pulmonary rehabilitation represent potential solutions. There are also a number of questions raised by this work, which raise questions for future research. How to improve the working relationships between GPs and other health care professionals? and how can the perceptions of health care professionals about referring patients for pulmonary rehabilitation be improved? are some such questions. Further studies on how best to improve service provision, and provide better information to health professionals and patients may be useful to address these issues.

Acknowledgements

We thank all the health care professionals who took part in this study and GlaxoSmithKline who provided a Medical Fellowship, Appeal No A0607280 to DH.

This work was been submitted as part of a Master’s thesis in Evidence-based Health Care to the University of Oxford, 2007.

References


**NICE.** 2004: NICE guidance no. 12, chronic obstructive pulmonary disease. *Thorax* 59 (Suppl), 84.


