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Experience based co-design to improve a Pulmonary Rehabilitation Programme

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Structured Abstract:

Purpose: To investigate patient perspectives on attending Pulmonary Rehabilitation (PR). This qualitative case study identifies the benefits and challenges to attending PR and presents improvements as recommended by patients.

Design/Methodology/Approach: A UK case study based on a Pulmonary Rehabilitation Programme undertaking focus groups (n=3) and interviews (n=15) with current and former patients.

Findings: The findings report the challenges and benefits of attending a PR programme along with recommendations on how the service could be improved.

Research limitations/implications: The authors focussed solely on a UK Pulmonary Rehabilitation programme, so the findings might not be applicable to other countries if PR is organised and provided in a unique way or setting.

Practical implications: This article provides valuable insights from patients attending PR programmes, which are useful to those running and designing these services.

Originality/value: The findings identify the benefits and challenges for patients attending PR programmes and suggests areas where improvements can be made.

Keywords: Pulmonary Rehabilitation, Co-production, Improvement, Patient-centred

Article Classification: Case study

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Introduction

Pulmonary rehabilitation (PR) is an effective intervention for patients with respiratory conditions, with improvements in exercise capacity, health-related quality of life and dyspnea (Lacasse *et al.*, 2006). There is also evidence for reductions in hospital stay (Griffiths *et al.*, 2000). Pulmonary Rehabilitation programmes are multi-disciplinary interventions tailored to patient's individual physical and social circumstances (Hutchings *et al.*, 2014). Although clinically effective, it is under-utilized with only 30% of referred patients completing the programme (COPD National Audit, 2016). Our purpose therefore was to understand the

challenges patients might face when referred to or attending a PR programme and to identify improvements, we undertook a UK case; patients were central to this PR case and the improvement activity. Patient and public involvement in improvement projects can be beneficial but requires careful management if its full potential is to be realized (Armstrong *et al.*, 2013). Justifications for involving patients in improvement projects are broadly similar to those for involvement in healthcare more generally. They include framing patients as the users and funders who have a legitimate stake in health services and are entitled to influence the service (re)design (Bate and Robert, 2007).. The research questions to be addressed by this qualitative case study are:

- What are the enablers and barriers to patients accessing the service?
- How do patients perceive the programme?
- What are the opportunities for improving the programme as defined by patients?

Pulmonary rehabilitation

In the UK, NICE (2011) and the British Thoracic Society (2014) issued guidelines for PR programmes in relation to participant selection, session numbers and timing, exercise intensity and type, educational, psychological and behavioural components, oxygen supplementation and outcome assessment. Often PR classes have long waiting lists with referrals coming from several sources including respiratory consultants, GPs and specialist nurses. Dropout rates and patients not attending is often an issue for those managing and running the classes (Healthcare Quality Improvement Partnership, 2018). Those patients who complete the course (usually between eight and twelve weeks) often find themselves wanting to continue (Williams, 2017).

Quantitative studies dominate the research assessing the PR programmes benefits. There have been a few qualitative studies focusing on PR effectiveness, conducted from a patient perspective (Monnikhof *et al.*, 2002; Bulley *et al.*, 2009). A recent study expanded these views to include staff and patient's significant others (e.g., relatives, friends) perspectives (Hutchings *et al.*, 2014). All these studies focus on identifying from varying perspective the positive and challenging PR aspects. None has explored from a patient perspective how PR programmes could be improved or identified where in the patient journey (i.e., from the initial referral to attend PR to discharge to maintenance classes) are the critical points where patients are likely to drop out or not attend, despite there being a strong rationale for enhancing patient uptake and PR completion (Jones *et al.*, 2010).

This study responds to the call for further research, particularly single-intervention strategies tailored to the key barriers that are relevant to the PR setting; e.g., Nici and ZuWallack (2012) emphasise the need to understand poor patient participation and retention as critical to being able to design strategies in which to improve participation. A mixed-methods review of participation in PR programmes attributed patient non-attendance and dropout to personal, clinical, social and physical barriers (Keating *et al.*, 2011). Only one respiratory self-management programme study explored reasons for high or low attendance, and the findings comprised socio-demographic, personal and clinical factors (Sohanpal *et al.*, 2012). It is suggested that socio-demographic and clinical factors may be insufficient to understand poor participation in these programmes; a new approach is therefore needed (Smith and Partridge, 2009; Michie and Prestwick, 2010; Hogg *et al.*, 2012).

Sohanpal *et al.*, (2012) thematic synthesis on self-management and pulmonary rehabilitation programmes literature found that understanding patient beliefs or perceptions towards their illness, the support programmes including the physical and practical concerns related to patient attendance, and social influences, can all lead to programme attendance, non-attendance, or dropout behaviour. For professionals involved in caring for patients with chronic disease, the review highlighted of the need for patient engagement (Efrimsson *et al.*, 2011)

and prioritising discussions about their illness and its treatment (Chew-Graham *et al.*, 2011) for improving motivation and longer-term participation in the treatment. During patient engagement, it is important for healthcare professionals to explain how the programme benefits the patient in relation to the outcome/s patients would like to achieve for themselves, including the expected benefits after attending only a few sessions and in the longer term. Encouragement and reassurance to patients that the programme can help them learn strategies to gain control, cope and remain independent is critical alongside smoother referrals (Johnston *et al.*, 2013 and travel arrangements for improvement in patient participation. To help facilitate this, professionals require training and support, (Zwar *et al.*, 2012) increasing access to programmes in areas local to patients and creating awareness and better communication about service provision (Yohannes *et al.*, 2011).

Case study

This qualitative case study focuses a PR programme based in Solihull in the UK, which offers twice weekly two-hour sessions for eight weeks for up to 21 respiratory patients per class. The programme is one of eight programmes offered by Heart of England NHS Trust and is held in the hospital. The classes are also run at various community-based sites in the same manner. After referral, patients have a one-to-one assessment with a physiotherapist, where appropriate the patient will be added to the PR waiting list. The PR plan is a rolling programme (e.g., three new patients start, and three patients complete each week), which accepts referrals from GPs, consultants, respiratory nurse specialists and acute ward staff. To attend the programme, patients must have a respiratory diagnosis (e.g. COPD, Asthma and Pulmonary Fibrosis). The service is oversubscribed and often has a 27-week waiting list (around 61 patients). The service is run by a highly specialist physiotherapist, a specialist physiotherapist and a physiotherapy assistant. In 2015, the 'Did not attend' (DNA) rate was running at 22%, which led the team to want to see how they could improve the service to try and limit drop-outs and DNAs. The ethos the team adopted to improving the programme was based upon co-design principles.

Data and methods

Ethics approval was gained from the Wales REC Committee 1. Three focus groups were held with patients who had attended PR in the preceding six months. One hundred patients were invited by letter to attend. In total 33 current and former patients attended. The group discussions were between 45 minutes and an hour long. The focus groups were purposely informal and patient-led. The focus groups were supported by two facilitators to ensure that all discussion points were captured. Additionally, individual experience-based semi-structured interviews were conducted with 15 patients who completed their PR programme. These participants were identified and invited to participate in the study whilst attending a respiratory clinic. The interviews were held at the patient's home and lasted approximately 45 minutes. The interviews and group discussions focused on patients PR experiences, what they liked about the programme and what could be improved. Participants were asked for ideas on how improvements could be made. The focus groups and the interviews were audio-recorded and transcribed. For reliability and validity the interview and focus group data were triangulated and compared, the transcriptions were checked and coded by two researchers and the anonymised results were presented to the local patient respiratory groups. Anonymised participant quotations are included in the findings using a P1, P2 notation.

Data analysis

The qualitative experience-based interview and focus group data were analysed using King's (2004) thematic analysis framework, an approach that allows for the development and clustering of conceptual themes (Cassell and Symon, 2004). Template analysis requires the

production of a code list or a 'template' which represents themes identified in the textual data (King, 1998). An initial template was constructed to analyse the data and identify codes. The initial template was based on the research topic and the themes that emerged from reading the first few transcripts. The analysis was an iterative process and the template and codes updated as new themes emerged. Key themes included: access; expectations; information; social interaction and improvements. From the qualitative analysis, it was possible to produce a high-level respiratory condition map (Figure 1) (e.g., Chronic Obstructive Pulmonary Disease (COPD)). From this analysis two critical points were identified: Exacerbations and Pulmonary Rehabilitation. We focus on the latter.

Figure 1 here

Findings

When patients were asked to describe their diagnosis journey and managing a respiratory condition, many referred to their frustration in not being able to do the things that they would like to or had done previously. Coming to terms with being less mobile or active was particularly distressing for some participants. For others, the PR programme helped them to understand their condition and they welcomed the opportunity to share experiences with others in a similar position. From analysing participant experiences, it was possible to construct a generic high-level process map (Figure. 1). It was also possible to map the pulmonary rehabilitation programme, which includes patient and information flows and the main enablers and barriers to accessing the programme (Figure 2). In addition to visualising how patients access the PR programme, a thematic analysis of the focus group and interview data identified six key themes. The themes are presented as they emerged from the data and not ranked by importance.

Managing expectations

Most participants could explain their referral to physiotherapy to be assessed for pulmonary rehabilitation. However, the information they received about the programme was variable depending on how and who made the referral. If participants had met a physiotherapist or specialist nurse they were more likely to have a clearer understanding and knew what to expect from the PR programme. Often participants had been presented with information from their GP or because of attending a clinic appointment and in these cases, participants were less clear what to expect. Some participants noted there was a long wait between having an initial discussion with either the GP, specialist nurse or consultant and follow up assessment by the PR team. For those participants, not used to doing any physical exercise, recalled their apprehension to join the PR programme.

Accessing and leaving the PR programme

Some participants relied on hospital transport to enable them to attend the PR classes. Several respondents recalled times when they had arrived late for the class and had to wait several hours before they could return home. As one patient noted 'this makes a very long and tiring day and concern to whether the next trip will be the same' [P3]. Several interviewees reflected on whether the timing for the referral to PR programme was right for them. Reflecting on the benefits accrued from attending the classes and particularly for those participants that had continued with the maintenance classes they thought they could have been referred sooner. Some participants were unclear about what had changed in their condition to trigger a referral to PR. Others recalled the referral being triggered by an admission to hospital or the attendance at a respiratory clinic.

Most participants were unclear about when they would be leaving the PR class and where or what they could move on to. Some participants who had completed their programme spoke about their preference to continue with the PR programme, but recognised there were other patients waiting to attend: ‘.. I loved it [PR], I didn’t want to leave. And the improvement, it really, really helped’ [P1]. The fact that the PR programme is supported by specialist clinical staff was a key benefit and something that participants referred to as missing from the maintenance classes. Two participants recalled the difficulties fitting in PR activities while working. The opportunity to attend weekly sessions was impossible for one participant who was working full-time. Two other participants who were also working relied on the flexibility offered by their employers to enable them to attend the eight-week course.

Information and communication

Participants were unclear as to where and what information they had received about PR before joining the programme. All participants felt the information given about the first appointment and what to expect could be improved. Particularly the commitment that is required from patients (e.g., twice weekly attendance for eight weeks). The information about PR was reported to be inconsistent from different sources; i.e., GPs, practice nurses, with some referrers being unclear as to what PR entails. Participants recognised getting the balance right; i.e., providing enough information to prepare the patient for attending pulmonary rehabilitation and not frightening them was difficult. One participant recalled whilst attending a clinic appointment ‘I was given a lot of information on paper, which I’ll be quite honest ... Was it helpful? Sort of ... what I read ... I get bored with reading’ [P14]. Another patient commented: ‘... she just gave me some leaflets, and then I had a letter come through the post I think, and it was a leaflet, I remember looking at them, I thought ... I haven’t got to do that have I?! And I thought, well I can’t go on the way I am.’ [P2].

Education and self-management

The PR education sessions which are part of the programme were particularly well received by all participants and many noted how these improved their understanding and management of their condition. For example, ‘then there’s like lectures, if you want to call it that, but good advice on how you can help yourself and things to do for yourself’ [P11]. Several participants found the educational sessions helped them to better understand COPD and the self-management required. The sessions around inhaler user, breathing techniques and general information about respiratory conditions were popular. The handouts that accompany the talks are well received and are often referred to many months later. Having the opportunity to hear what healthcare professionals had to say about their conditions was helpful but also reassuring.

Social contact

A key benefit of PR (and the maintenance classes) reported by some participants was the opportunity to meet others in a similar situation. The ability to share experiences and to see how people progressed was beneficial and motivational. As one participant commented ‘But it’s nice to go there [PR] as well because you know a lot of the people there. So that’s good too. So, it is actually, most of it is knowing people who understand how you are’ [P9]. Another participant commented: ‘The camaraderie, just you could have a laugh, you know, you didn’t think about what was ailing you and ... you sort of forgot about that and you were able to do better.’ Another participant recalled hearing about her local Breathe Easy group (patient-run monthly meeting supported by the British Lung Foundation) whilst attending PR, which enabled her to stay in contact with fellow patients after she had completed the PR programme. One participant also noted the friendships made through attending Breathe Easy group meetings: ‘You know, my friend from Breathe Easy will phone me up and she’ll say, oh I’m

phoning you up ... because I know you know how I feel' [P11]. Several participants mentioned the different speakers attending the Breathe Easy meetings were also a way to learn about their conditions and updated on the services available to them.

Motivation and sustaining the gains

The fact that exercises were designed to be done at home was described by several participants as being hugely beneficial; e.g., one participant commented 'Each exercise ... they're so simple, you can adapt them for home you see ... all these exercises they give you are easily adaptable ... And I found that my lung functionality really improved over the eight weeks, which encourages you to do it at home as well, so you know, when you're fit enough' [P10]. However, some participants recalled the difficulties of maintaining motivation to attend maintenance classes. There were various reasons, which included difficulties accessing the classes; one participant recalling the class being held some way from the bus stop and being extremely breathless when he arrived. One participant described the maintenance class as 'just not being the same as the PR class' he felt his condition was not understood the same by at the maintenance staff. He went on to describe the reassurance gained from specialist physiotherapists and the ability to ask specific questions about his condition.

Pulmonary rehabilitation pathway

Figure 2 illustrates a high-level pathway map of patients accessing and attending PR classes which was first drafted from the patient interview data. The map was then presented to members of the PR team and other patient groups (e.g. Breathe Easy) to ensure it represented the key steps within the pathway. Typically, at the start of the pathway the physiotherapists receive a referral via letter, fax or more so by email. The referrals come from various stakeholders including respiratory consultants, specialist respiratory nurses, Practice nurses and GPs. One-to-one assessment of an hour is conducted at the start of the process. This assessment can be reduced to 30 minutes if the patient has already been seen by community respiratory nurse specialist and details of the assessment are included with the referral. If the patient is suitable to attend the class their name is added to the waiting list. It is a rolling programme which allows for up to three new patients to join the class each week.

Figure 2 here

Once the patients have completed eight weeks (16 sessions), they are discharged. The dotted lines on the map denote the organisational boundaries, which patients need to cross. Often it is at these boundaries that either the information and/or patient flows are interrupted or stopped; e.g, the full referral details may not reach the physiotherapists or patients may choose not to attend the maintenance class. From participant feedback, it would appear where there is a boundary spanning object/person in place, the flows are less likely to be interrupted or halted. These boundaries are critical points that need to be managed well to ensure information and patients flow seamlessly and without interruptions or delays. Providing dedicated resource to 'join up' services should assist with the DNA and drop rates. Additionally, they should help patients to sustain self-management and regular attendance to maintenance classes.

Discussion

It is evident from our qualitative data that patients do not feel sufficiently informed about the potential benefits gained from attending a PR programme, the reasons why they have been referred or what they might expect. As noted by Yohannes *et al.*, (2011), there is a need to increase PR awareness and improve the communication about service provision. Our research has provided an insight directly from patients about their experiences and the benefits they

gained from attending R programmes. The engagement with patients has been central to this case study as advocated by Efraimsson *et al.*, (2011). From our analysis, improvements to the PR programme have been identified and actioned.

Improvements to the Pulmonary Rehabilitation Programme

Several improvements have been identified, and in some cases, redesign activities are underway. Improvements focused on communication and information and transition points within the pathway.

Information flows

From the analysis, it was evident several critical information points require attention. When patients are transitioning referral points this is where drop-out may occur. These points need to be supported with good communication and information (Cooper *et al.*, 2015). It is evident from this study that the information can be various formats; e.g., leaflets, letter, email and website. To ensure that the information is available at the right time for the patient requires good signposting. There is a patient-led redesign programme underway that aims to review the PR information provided to patients. To ensure patients are clear about the PR programme duration it was suggested that an agreed estimated discharge date is provided on the individual exercise sheets from the initial PR session. This would need to be revised if patients were unable to attend the programme owing to illness or other extenuating circumstances. This discharge date is then discussed and agreed with the patient when the follow-up exercise test is booked. Visualising the date will also help to clarify the completion dates for patients, which again could assist with ensuring patients attend all their allotted sessions.

Transition points

Participants reported that arrival at a PR class for the first time can be a frightening and stressful experience. Since conducting this study, the PR team introduced a buddying system where 'volunteer (former) patients' are available to 'meet and greet' new starters to the class. Being welcomed by a patient buddy that has already completed the programme has been received well by patients and seems to alleviate fears that new patients might experience. The transition to maintenance classes is a critical point where patients may be lost. Several participants raised the issue that 'maintenance classes are not the same as PR and the instructors not fully understanding their condition'. All maintenance instructors are British Lung Foundation Active Instructors, but as a result of the feedback the education programme now includes discussions around moving on from PR, and what to expect at the maintenance classes, to help manage participant expectations. Patient buddies are also placed within the maintenance class to help with the transition. Often it is the same buddies that volunteer at the PR programme that are at the maintenance class. One issue with the maintenance classes for patients is not having a specialised physiotherapist present. Unfortunately, NHS funding and commissioning models are not able to accommodate these specialist resources being available in maintenance classes. To further manage the transition, it is planned that maintenance instructors will visit PR classes on a monthly visit to meet potential new recruits and help support the work of the instructors in the maintenance classes. This will be enhanced by visits from the specialist physiotherapists from the PR group.

Implications

It is our intention to follow up with further focus groups annually to enable the team to ensure PR continues to meet patient needs. Our results have been used to redesign the existing service, as described above. This experience-based approach ensures that the patient voice is captured and is central to service redesign (Bate and Robert, 2007). This study has highlighted the

critical points in the patient PR journey where specific interventions may assist in ensuring service continuity when patients and information crossing organisational or functional boundaries. Quality improvement projects/interventions needs to ensure that information flows and patient flows are considered. How information is provided and used within patient pathways needs to be mapped (at a high level is usually sufficient) to visualise critical points where teams need to focus their efforts; e.g., in this project referral or transition points in and between services.

Limitations

This case study is limited to one UK PR service. However, the results from this study should assist healthcare professionals in (re)designing PR services or similar rehabilitation services. We have demonstrated the value of gaining patients and relatives' perspectives in relation to re-designing services. Further research is needed to explore staff perspectives and to further engage with patients to evaluate and prioritise the recommendations put forward for improving the PR programme. Although an economic analysis was outside the remit of this study a cost benefit analysis is needed to evaluate the impact on key indicators such as hospital admissions and length of stay. Such data are critical to PR programme design and development.

Conclusion

Pulmonary Rehabilitation is an evidence-based exercise and education intervention for patients with a respiratory-related condition. This UK case study identifies from a patient perspective some key benefits and challenges attending PR programmes. Several improvements have been identified, some have been addressed within this case study. Although there are limitations as noted above, there are implications for those that are involved in delivering and designing PR and other rehabilitation programmes. This study has encouraged patients to share their experiences, which enabled high-level maps to be constructed. These have helped to identify transition points. The information flows and good communication were identified as being important to the current and future PR programmes.

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