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Project title: Improving uptake of post-hospitalisation pulmonary rehabilitation using a patient designed video

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Plain language summary

What is the problem?

Pulmonary rehabilitation (PR) is a lung fitness programme that consists of exercise training and education designed to improve the breathing, quality of life and walking ability of patients with long term lung problems such as Chronic Obstructive Pulmonary Disease (COPD). Following a hospital admission for flare-up of COPD, PR helps improve breathlessness, quality of life and walking ability, and reduces the risk of repeat hospital admission. However, less than 10% of COPD patients receive PR after hospital admission. Previous interviews of patients showed many did not understand what PR involved and some were scared that they were too ill to exercise. Many felt more likely to attend PR if there was a more thorough explanation in hospital.

What did we do?

Using video interviews of patients who had been in hospital and/or received PR, we held a series of patient / staff events to produce a 5-minute video designed for patients with COPD due to be discharged from hospital. We conducted a small scale practice study where patients with COPD, on the day of hospital discharge, either watched the video and received an information leaflet (intervention group) or received the information leaflet only (usual care group). 15 patients (some from both groups) and 7 staff were interviewed to gather views of the video and experiences of PR (if attended) and their experiences of the research process.

What did we learn?

Patients and staff thought the video was well presented, the right length and that the information presented was clear. Suggested improvements included: more cultural diversity of filmed participants; subtitles for the hard of hearing. Experiences of PR were positive. The video was best played using a portable tablet device as many hospital wards did not have bedside media systems. Many patients did not attend the 3-month follow-up hospital visit. The answers to the questionnaires did not have enough information to work out health costs accurately.

What happens next?

Funding has been obtained to conduct a larger scale trial to test whether the video helps persuade more people to go to PR after a hospital admission. This may help more people with COPD recover quicker from a hospital admission and reduce the risk of further hospital admission. Based on the small-scale practice study, we have made changes to how the large trial will be performed, such as the option of home visits, telephone follow-up and changes to questionnaires.

Keywords

COPD, pulmonary rehabilitation, hospital admission, video intervention

Summary of research findings

Background and Rationale

Chronic obstructive pulmonary disease (COPD) is the third most common cause of death worldwide. In the UK, acute exacerbation of COPD (AECOPD) is the second commonest cause of emergency hospital admission, representing a high economic burden to the NHS and society.

Pulmonary rehabilitation (PR), a multi-disciplinary package of care comprising exercise training and education, delivered within four weeks of hospital discharge for AECOPD, improves exercise capacity, quality of life and breathlessness, and has been shown to reduce the risk of hospital readmission. Post-hospitalisation PR is recommended in national guidelines and is now a NICE Quality Standard. However audit data shows that less than 10% of patients hospitalised with AECOPD receive PR. The majority of missed opportunities occur at the initial referral stage with most patients declining offers of referrals.

Emergent themes from a previous qualitative study conducted by the applicants to understand the barriers to PR from a patient's perspective included "no understanding of what pulmonary rehabilitation involved", "no memory of being offered PR", "too unwell to exercise" and "scared that exercise would make things worse". When asked about potential ways of addressing these issues, a common theme was "hearing about what happens from a patient who's gone through it before" and "knowing that people as bad as me have done it and benefited".

Aims and Objectives

The aims and objectives of the research were 1) to develop, through accelerated experience-based co-design, a patient focused video with the intention of promoting post-hospitalisation PR; 2) to conduct a feasibility study of delivering this video with the view to optimising inclusion/exclusion criteria, recruitment strategy, study design and outcome measures; 3) to conduct a qualitative study to gather patient / staff views and attitudes of the video intervention, experience of PR and the research process to inform the design of a future randomised controlled multicentre trial.

Methods

We used an accelerated experience based co-design (EBCD) approach to develop the video intervention, comprising three events (staff, patient and joint staff/patient). Previously collected video footage was edited to produce a 5-minute video. A feasibility study was then conducted in 80 hospitalised patients with AECOPD randomised on the day of discharge to receive either the video and a patient information leaflet regarding PR, or a patient information leaflet alone. Fifteen purposely selected patients and seven members of staff were interviewed to capture their perspectives about the video, their experiences of post-hospitalisation PR (if attended/delivered) and their experiences of the research process.

Main Findings

A significant proportion of patients were discharged from the medical assessment unit where there was no access to bedside media systems. The video was therefore best delivered through portable tablet devices with headphones to minimise background noise and ensure fidelity of treatment/control allocation. Patients and staff thought the video was well presented, a good length and that the information presented was clear. Most patients and staff stated it was helpful to see patients with lung conditions in the video talking about their experiences and the benefits of rehabilitation. Patients also thought the video imparted more information than a leaflet, whilst staff thought the video was an excellent resource for patients to see prior to the referral process. Suggested improvements included: more cultural diversity of filmed participants (patients and staff); more about community centres - some patients were intimidated by specialist exercise equipment in hospital settings. Experiences of post hospitalisation PR were positive with all patients completing PR reporting improvements in their physical activity such as walking and carrying out activities of daily living. Social aspects were also important. There were no adverse findings about the research process for patients or staff.

The feasibility study revealed a slower than expected recruitment rate (averaging 6-7 patients per month). Although research consent rate of approached patients was high at over 80%, a significant proportion was excluded due to previous experience of pulmonary rehabilitation. Potentially eligible patients were also not recruited due to researcher unavailability. Mean time to deliver the intervention was 8 minutes. Completion of the disease-specific and generic health status questionnaires (CAT and EQ-5D-5L) was 100% on the day of discharge; in addition a patient cost questionnaire (designed to record healthcare usage from NHS and societal perspective) was designed and administered. There was significant missing data regarding the patient cost questionnaire, and attendance at the planned three-month follow-up time point was poor (less than 50%). Overall the adherence to health economic data collection was poor and data collection instruments required revision. Without un-blinding, the combined overall uptake rate of post-hospitalisation PR for the study cohort was 35%.

Expected impact on relevant field and conclusions

From the results of the research, changes were made to the trial protocol including inclusion/exclusion criteria, offering the option of home- or telephone-based follow-up at the three-month time-point and revision to the collection method of healthcare usage data. Additional funding was secured in October 2016 from the Pfizer OpenAir competition to

extend the recruitment of the single-site study (n=100 in each treatment arm) in order to provide greater accuracy in estimating efficacy endpoints. Recruitment is estimated to be completed by summer 2017. A recent systematic review identified no trials designed to increase the uptake of post-hospitalisation PR, and so the results of this trial, be they positive or negative, will be novel and of significant interest to the field.

Patient and public involvement

There was significant patient and public involvement in this project. Study 1 involved the design and production of the intervention – the patient education video. We used accelerated experience-based co-design (EBCD), which comprised a series of events including a patient event as well as a joint staff-patient event. The patient feedback from these events was extremely helpful in identifying the key themes to be included in the video and in the editing of the final product. Both patients and staff felt these events were highly positive with a true sense of collaborative working. Some of the patient contributors to these events ended up with starring roles in the final video! An unexpected outcome was that patient participants from the EBCD events decided to form a local patient support group (Harefield Breathing Support Group), which continues to flourish and meet on a monthly basis. This group has played an active role in providing patient-led education sessions as part of the pulmonary rehabilitation clinical service and in the dissemination of research. As a research team, we found the EBCD process very constructive and relevant to service quality improvement in the NHS, and have adopted this approach for other projects.

The qualitative component of the research project comprised face-to-face interviews with patients. This provided largely positive feedback regarding the content of the video; in particular, patients felt it was helpful to see hospitalised patients with lung conditions in the video talking about their experiences and the benefits of rehabilitation. Patients also thought the video imparted more information than a leaflet: “because you can tell from the patients themselves what they got out of it....no the video’s better.” The qualitative interviews also suggested improvements to the video including wider cultural and age diversity of filmed participants; more about community pulmonary rehabilitation centres; more about breathing exercises; and subtitles for the hard of hearing.

Experiences of post-hospitalisation pulmonary rehabilitation were positive with all patients who completed rehabilitation reporting improvements in their physical activity such as walking and carrying out activities of daily living. Social aspects were also important. There were no adverse findings about the research process for patients or staff.

Data sharing statement

See link

[\[https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253\]](https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253) for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

Disclaimer

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This project was carried out between August 2014 and January 2017. This final report has not been peer-reviewed. The report was examined by the Programme Director at the time of submission to assess completeness against the stated aims.