

Experiences of patients undergoing pulmonary rehabilitation during an exacerbation of chronic respiratory disease

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Abstract

Chronic obstructive pulmonary disease (COPD) is characterized in the later stages by acute exacerbations that often require hospitalization. Pulmonary rehabilitation is recommended for patients with COPD to aid symptom control, improve quality of life and increase physical activity. We have previously reported a large intervention trial commenced during a hospital admission. The aim of this sub-study was to evaluate the patients' experiences of discharge following the hospitalization for an acute exacerbation of COPD. During a programme of early rehabilitation (ER) patient perceptions, experiences and healthcare use were collated during the month that followed their discharge. ER (started during their admission) was comprised of exercise training techniques that were modified to suit the environment of acute illness, together with an education and self-management programme. Each patient was then supported on the programme by telephone contact, following their discharge home, at 48 hours, 2 weeks and 4 weeks. We collected information in relation to the walking and exercise progression; we monitored patient recall of healthcare use, compliance/understanding of medical therapy, as well as their wider perceptions that may have influenced the recovery process. Healthcare use was captured using GP records and data analysis. Of the 100 patients, 47 males, (mean (standard deviation)) 71 (9.3) years, FEV₁ 1.14 L (0.6), BMI 26.6 (6.9), pack smoked years 45.8 (29.6), ethnicity White British 97%, were discharged home following an acute exacerbation of their respiratory symptoms, to an ER programme. At 48 hours following discharge, a minority (20%) of patients stated their symptoms were 'feeling better'; 15% highlighted that they found the prescribed 'exercise difficult'; 44% of patients felt at the end of the month that prescribed exercise programme had a 'positive effect' on their recovery from their exacerbation; 38% of patients felt their family had a positive effect on their recovery; 11% felt their family hindered. Patients reported a mean confidence score of 8.21 (2.1) for exercise that did not vary over the three contacts ($p = 0.166$). A similar mean confidence score of 7.76 (2.6) was reported for walking with a non-statistical change also noted ($p = 0.223$). When patient recall of primary health care contact was compared with actual use, there was statistical significance shown ($p = 0.002$); patients underestimated the amount of care they received. The data indicate that patients do recover at home within the support of an early

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intervention. Patients are positive about the benefit of ER in the process of recovery; however, this is uncontrolled data.

Keywords

Pulmonary rehabilitation, chronic obstruction pulmonary disease, exacerbation, patient experience

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Introduction

Chronic obstructive pulmonary disease (COPD) is characterized in the later stages by acute exacerbations that may require hospitalization. An exacerbation is defined as ‘A sustained worsening of the individual’s symptoms from their usual stable state, which has a rapid onset. Commonly reported symptoms are worsening breathlessness, cough and increased sputum production and change in sputum colour.’^{1–3} Exacerbations can be frightening for the patient and may greatly affect their quality of life, thus causing a gap between desire and achievement in everyday activity. Patients who have frequent exacerbations often have a worse quality of life than those with infrequent episodes and are more likely to become housebound.⁴ In turn, they may incur a greater loss of functional capacity and increase their risk of another hospital admission. This is true for COPD but is likely to be equally important for other chronic respiratory diseases (CRDs) such as interstitial lung disease and bronchiectasis.

The immediate post-exacerbation period often incurs an increased sense of vulnerability to the patient. The ‘Ready for Home’ Survey,⁵ commissioned by the British Lung Foundation (BLF), highlighted that the majority of patients with COPD needed more information and support when being discharged home from hospital with an exacerbation. The survey concluded that many patients did not feel adequately prepared when they are sent home. Further research⁶ highlighted very similar difficulties experienced by patients during this vulnerable time and also found that resuming life at home following an admission was difficult for patients.

Pulmonary rehabilitation (PR) is recommended for patients with COPD to aid symptom control, improve quality of life and increase physical activity.² Findings from a recent large randomized controlled trial of an early rehabilitation intervention³ suggest that caution is needed when delivering an intervention during an exacerbation.

The aim of this study was to evaluate the patients’ perceptions to discharge following their hospitalization of an exacerbation of COPD and their commencement of an ER intervention.³ Patient perceptions, experiences and healthcare use were collated during the month that followed their discharge. Our objective was to provide both qualitative and quantitative outcome data that may facilitate informed decision-making between patients and professionals to enhance recovery following discharge.

Methods

This study was part of a larger, prospective, parallel group, single-blind, randomized controlled trial conducted at the Glenfield Hospital, University Hospitals of Leicester and Kettering General Hospital.³ The REACH trial investigated a progressive, exercise intervention that was delivered immediately following an unscheduled admission for an exacerbation of CRD. The intervention commenced shortly after patient consent and was comprised of exercise training techniques that were modified to suit the environment of acute illness, together with an education and self-management programme. Each patient was then supported on the programme by telephone contact, following their discharge home, at 48 hours, 2 weeks and 4 weeks. No other follow-up was offered in the community.

Participants

The inclusion criteria were diagnosis of CRD (COPD, chronic asthma, bronchiectasis and interstitial lung disease), self-reported breathlessness on exertion when stable (MRC dyspnoea grade 3 or worse) and age 40 years or greater. The exclusion criteria were inability to provide informed consent, acute coronary syndrome, presence of musculoskeletal, neurological or psychiatric comorbidities and more than four emergency hospitalizations in the previous 12 months.

The data collected for this sub study are for the intervention participants of the Glenfield Hospital, one of the two sites only.

Consent and randomization

Once informed consent was obtained, participants were randomly allocated to the ER group within 48 hours, using an automated Internet-based randomization service (www.sealedenvelope.com) coordinated by the Clinical Trials Unit at University Hospital of Leicester.

Ethical approval was given for the study by the National Ethics Service (NRES) Nottingham Rec 1 Committee (09/H0403176) and the study was registered on the ISROTN (N05557928).

Intervention

The ER group received daily supervised volitional (strength and aerobic training) and non-volitional (neuromuscular electrical stimulation (NMES)) individualized training until their discharge. In addition, patients were introduced to a self-supported management programme, SPACE, for COPD⁷ during hospitalization. Following discharge, patients were advised to follow a progressive walking-based home programme, continued daily NMES and were encouraged to follow the self-management programme. This was supported by telephone consultations, using motivational interviewing techniques, at 48 hours, 2 weeks and 4 weeks. Details of the hospital and home-based training regimens are provided in Appendix 1 and have been previously described.³

The telephone consultations were conducted by the PR team members; the first author inclusive. They followed a semi-structured format (as shown in Appendix 1). We collected information in relation to the walking and exercise progression and monitored healthcare use, compliance/understanding of medical therapy, as well as the wider perceptual themes that may have influenced the recovery process, such as their perception of how useful the exercise was in relation to recovery, and the impact that their family had upon the process.

Healthcare use was captured using GP records and data analysis. We documented all contacts, including telephone consultations with the GP or practice nurse and compared this to patient recall. We were interested in understanding how often patients used their primary care services and their recall of this. Every telephone call, to each patient, was documented within the patient's notes.

Outcome measures

Sources of qualitative data

1. Self-reported patient perceptions of their experience resuming recovery in the month following their discharge (assessed by the use of an open-ended question). On each contact, patients were encouraged to comment on their recovery, and how they were coping with the prescribed exercises following their admission.
2. Perceived healthcare use. On each phone contact, patients were asked to recall the number of GP and community visits/calls that they received during the month following their discharge.
3. The patients' perceived benefit of completing the exercises at home. On each phone contact, patients were asked if they felt the exercises were beneficial to their recovery.
4. The patients' perception of family influence over their recovery. On each phone contact, patients were asked if they felt their family/carer had supported their exercise programme.

Sources of quantitative data

1. Likert scale (1–10) confidence scores (to assess their level of confidence to continue their progressive walking and exercise at home).
2. The number of positive and negative perceptions noted at each phone consultation in relation to their recovery process (using thematic analysis⁸).
3. Actual healthcare use (visits/calls) of GP and primary healthcare teams. The GP records of all the participants were obtained. We recorded every point of contact they received from all primary healthcare services in the month following their discharge.

Data analysis

Boyatzis'⁸ thematic analysis method was adapted to code and analyse the perception data collected; coding is the primary process for developing themes with the raw data. This is achieved by recognizing essential patterns and encoding into theme development for collection and analysis.

Initially, the primary author read all of the notes for every patient, analysing the data with open coding for themes and sub-themes, for each set. This process continued until data saturation was reached and no new themes evolved. The coding was then

subsequently reviewed by two independent researchers for the discussion of coding and discrepancy of interpretation. The formation of theme ‘codes’ was then resolved by the consensus of three researchers. This process encourages consistent data coding and enhances the dependability of the findings.⁹ Following agreement, two of the researchers returned to the original text of the transcripts to confirm that the themes were compatible within the original context, thereby enhancing the credibility of the data transferability.¹⁰

Statistical analysis was completed using Statistical Package for Social Science (SPSS) software (version 18). Baseline values are described as mean (standard deviation) differences.

The mean changes of confidence scores for walking and exercise, numbers of positive and negative perceptions, length of call and healthcare utilization are presented, and *p* values were calculated by using Green–Geisser analysis of variance to demonstrate the magnitude of change, *p* < .05 significance.

Results

Of the 100 patients, 47 males, 71 years (9.31), FEV₁ 1.14 litres (0.60), BMI 26.62 (6.92), pack smoked years 45.80 (29.63), ethnicity White British 97%, were discharged home following an acute exacerbation of their respiratory symptoms, to an ER programme.

There were three deaths during the month following discharge, with an additional four patients withdrawing from the study.

Patient perceptions

At 48 hours following discharge, only 20% of patients stated they were ‘feeling better’, 6% said they felt ‘more active’ and only 7% said they felt relieved to be home; in contrast, 15% highlighted that they found the prescribed ‘exercise difficult’, while 14% felt ‘tired’ – other perceptions are shown in Table 1. These were the primary perceptions collated from individual patients.

During the course of ER, there were a mean 1.13 (0.82) number of positive perceptions reported by patients with a non-statistical difference (*p* = 0.32) over the three contacts. Similarly, a mean 1.13 (0.94) number of negative perceptions were reported over the three contacts with a non-statistical difference noted (*p* = 0.94; Table 2). These positive and

Table 1. Recorded patient perceptions at 48 hours.

Themes	%
Relief to be home	16
Feeling tired	14
Feeling unwell	9
Feeling worried	8
Finding the exercise difficult	15
Feeling more active	2
Feeling generally better	20
Short of breath	8
Total	92
Missing data	8

negative perceptions were not analysed in detail like those at 48 hours.

Patient perceived benefit of exercise

Forty-four percentage of patients felt at the end of the month that prescribed exercises set had a ‘positive effect’ on their recovery from their exacerbation.

Patient perceived family effect on their recovery

Thirty-eight percentage of patients felt their family had a positive effect on their recovery, 11% felt their family hindered and 22% lived alone (missing data for 29%).

Confidence scores

Patients reported a mean confidence score of 8.21 (2.1) for home exercise, for which there was a non-statistical change over the three contacts (*p* = 0.166). A similar mean confidence score of 7.76 (2.6) was reported for walking with a non-statistical change also noted (*p* = 0.223; Table 3).

Patients recall of healthcare contact in primary care

Patients were asked to recall home visits and/or healthcare contacts from their GP or community nurses (Table 4). There was no statistically significant difference between the recall reported over the three times points (*p* = 0.322). However, when patient recall was compared with actual use, there was statistical significance shown (*p* = 0.002), with patients significantly underestimating their healthcare utilization.

Table 2. Number of positive and negative perceptions recorded at each call.

	48 Hours	2 Weeks	4 Weeks	Overall	<i>p</i>
No. of positive perceptions	1.27 (0.94)	1.12 (0.86)	1.06 (0.86)	1.13 (0.82)	0.376
No. of negative perceptions	1.45 (0.94)	1.26 (1.08)	1.06 (0.86)	1.13 (0.94)	0.302

Table 3. Patient's confidence scores for walking and exercise.

	48 Hours	2 Weeks	4 Weeks	Overall	<i>p</i>
Exercise confidence score (1–10)	8.01 (2.38)	8.27 (2.25)	7.48 (3.09)	8.21 (2.11)	0.166
Walking confidence score (1–10)	7.87 (0.80)	8.15 (2.50)	6.93 (3.45)	7.76 (2.6)	0.223
Average length of call (minutes)	6.58 (7.02)	9.40 (5.18)	9.35 (4.43)	9.55 (5.07)	0.004

Table 4. Patient recall compared with actual use of health-care services in primary care in the month following discharge.

	Patient recall	Actual	<i>p</i>
Healthcare use	0.91 (0.83)	2.97 (2.03)	0.002

Interestingly, the length of phone calls to the patients increased significantly over the month ($p = 0.004$; Table 3).

Discussion

This is the first study to investigate in detail the patient perceptions and experiences in the month following unscheduled hospital admission for an exacerbation of CRD. We firstly found that at primary contact (48-hour phone call), only 20% of patients stated that their symptoms 'felt better'. Another smaller, but sizable group (15%) did report finding the prescribed exercise programme difficult to continue with once they were at home. This may have been associated with the tiredness reported by an additional 14% of patients. However, despite the positive perceptions reported by the participants in the intervention, by the end of the programme, less than half of the patients (44%) felt that the set exercises had had a positive effect on their recovery from their exacerbation. The supportive narratives collected within this theme were 'improved functioning of activities of daily living' and 'generally feeling more myself'. This supports the theory that exercise encourages patients to cope better with long-term side effects and enhances the restoration of independence.¹¹ Acknowledging patients' psychological responses to treatment, such as 'feeling better', is

evidence of practitioners considering multi-systemic needs and the incorporation of holistic care. A greater depth of understanding will allow for an enhanced therapeutic relationship through empathy, acceptance and genuineness.

The BLF Ready for Home⁵ survey highlighted that patients felt they needed more support when they were discharged from hospital and thus felt unprepared to cope fully once they were home. The findings of our study did not reflect this. We noted an equal balance of positive and negative perceptions at every contact, implying some ability to master symptoms, and evidence of self-managing strategies.

The role of family support may have also influenced the positive experience of the programme. Social and environmental context of patient recovery is a significant consideration.^{12,13} Although 22% of our patients lived alone, 38% felt their family had had a positive effect, while only 11% claimed perceptions of hindrance. Carers who maintain a close relationship with the patient are likely to be affected by the illness and in turn alter the supportive network. Thus, the recognition of this potential impact is significant when providing an ER programme. Installing a sense of empowerment for patients and their caregiver is value bound and contextual to holistic care. It is interesting to note that this was not a direct question asked within the telephone format. Caregiver influence was a voluntary theme that was dominant within the section 'Is there anything else you would like to talk about?'

Enhancing the patient recovery process involves not only improving the positive effect of outcomes but also understanding intrinsic factors, such as personality traits, that may influence this process. Patients may feel particularly vulnerable following a hospital admission and by measuring their levels of

confidence practitioners can evaluate the likelihood of them being able to self-manage and adhere to treatment. During the programme, patients reported a high mean score in confidence when asked to comment on their ability to walk and exercise at home. Interestingly, we noted a statistically significant rise in the length of phone call as the month developed. It is possible that these two measurements may be related. In addition to the development of a therapeutic relationship, the increase in call length may indicate the necessity of time needed to promote the maintenance of confidence. The promotion of confidence building enhances patient independence through mastery and competence. Some patients seek sense of control over their illness. Early rehabilitation programmes may allow for a supportive environment, whereby frightening symptoms such as breathlessness can be put into a 'balanced' perspective and fearful emotive cycles may be broken. PR professionals aim to facilitate open discussions with patients and carers to establish emotional sensitivities and need.¹⁴

The phone calls were a small percentage of the help sought by patients during the month following their discharge home. Contact with healthcare providers for sufferers of long-term chronic conditions such as GPs and community nurses can generate trust, support and the belief of a hopeful recovery. We collected information regarding the scale of supported care that each patient required in addition to our three telephone contacts. It is worth highlighting that we found patient recall of healthcare use was significantly underestimated when compared with the actual service provided. This has not been previously reported in the population of CRD.

The acknowledgement of previous research findings^{15,16} related to cognitive disrepair following acute exacerbation may help to explain the difference in perception and the patient's ability to remember the varied healthcare contact. In addition, cognitive function may fluctuate during unstable exacerbations,¹⁷ and it is therefore possible that patients being discharged from hospital may have clinically significant but unrecognized cognitive deficit.¹⁸ This in turn can affect patients' recall and adherence to treatment. Our results also add caution to previous telecommunication studies¹⁹ suggesting that patient recall is relatively accurate and cost-effective.

This study has some limitations. A main limitation of this study is that we had no telephone contact with the group who were assigned to 'usual care'. Indeed, their perceptions of 'normal' recovery from an

admission from hospital would have been of great interest. It was recognized, however, that this was not possible, as the telephone contact may have influenced the recovery process, although they did in fact have a similar recovery, despite the lack of intervention.³ In addition, patient perceptions of early rehabilitation conducted during their hospital stay were not recorded. It is possible that these perceptions may have differed from those recorded following hospital discharge. Moreover, we were not able to distinguish the perceptions of early rehabilitation among patients with varying diagnosis. It was unfortunate that there were missing data related to the patient's perceived family effect upon their recovery. These are all important areas for further study.

The thematic analysis from this study has directed meaning from patient narratives and has added to the objective measurements taken. The programme of ER appears to be acceptable to patients; however, the extent of contact had with a health professional does not always appear to be recognized or remembered; even within a relatively short span of time.

The ER programme ensured continual care assessment, motivational interviewing and a prompt recognition of need. In addition, there was the provision of support, comprehensive information and the monitoring of functional ability. Cognitive, emotional and medical needs were observed and aligned with the wider impact of family influence and the value of exercise; all of which appear to have had a positive effect upon the patient. These data are unique. These data question previous findings^{5,6} and imply that patients can recover at home within the realms of guided self-management and the support of their family. Moreover, the patients are able to see the benefit of ER in their process of recovery. The results of this study support wider investigation of early support programmes for those patients with an exacerbation of CRD. An understanding of the complex variables that play in the management of CRD may help to improve patient quality of life and in turn adherence to therapy.

Author note

The views expressed are those of the authors and not necessarily of the NHS, the NIHR or the Department of Health.

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Author contributions

EEV, JEA, SJS, MCS, NJG, EJC, TH-D and MDM contributed to study design. EEV was the principle investigator for this sub-study. EEV, EJC, JEA, TH-D, NJG, SJS, MCS and MDM undertook the recruitment and performed the study. All authors contributed to data analysis. EEV wrote the manuscript which was reviewed for academic content by SJS.

Declaration of conflicting interests

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Appendix I

Telephone format. Telephone Call Log – 48 hours after Discharge (Intervention Group only)	
Date:	Randomisation No.
Caller ID	
1). How do you feel now you are back home?	
2). Do you feel your symptoms are generally getting better?	
	Yes No
If no, do they need referring to REDS	<input type="checkbox"/>
GP	<input type="checkbox"/>
Community Matron /SPRINT	<input type="checkbox"/>
ROCKET	<input type="checkbox"/>
3). Did you receive the manual before discharge?	Yes No
If no, organise for one to be delivered	Date.....
4). Are you happy with your walking programme?	
<i>On a scale of 1-10 how confident do you feel you will be able to carry on with this?</i>	
5). Are you happy with your strength programme?	
<i>On a scale of 1-10 how confident do you feel you will be able to carry on with this?</i>	
Length of Call.....	
Telephone Call Log – 2 weeks after Discharge (Intervention Group only)	
Date:	Randomisation No.
Caller ID	
1). Are you finding the manual helpful?	Yes No

6). Any course of antibiotics
 steroids

7). Any questions?

Length of Call.....

Telephone Call Log – 4 Weeks after Discharge (Intervention Group only)

Randomisation No.

Date:

Caller ID.....

1). **Are you finding the manual helpful?** Yes No

2). **Strength programme**

End of previous week:

	Bicep Curls	Pull Ups	Sit- Stand	Step-ups
Weight				
Repetitions				
How Hard?				

Where are you now?

	Bicep Curls	Pull Ups	Sit- Stand	Step-ups
Weight				
Repetitions				
How Hard?				

On a scale of 1-10 how confident are you of being able to continue with the exercises?

Randomisation No.

3). Walking programme

End of previous week	Time	Borg
Where are you now?	Frequency per day Time	Borg

On a scale of 1-10 how confident are you of being able to continue the walking?

4). Any visits to GP practice? regular check up's
..... practice nurse
..... GP

5). Have you had any emergency visits to the hospital for your respiratory disease?
.....visitsdays

6). Any course of antibiotics
..... steroids

7). Any questions?

Book appointment for 6/52 measures Date.....
Time.....
Letter sent

REMIND PATIENT to bring back any equipment and that they will have an activity monitor and questionnaires sent out to them which they'll need to wear/ fill out and bring with them to their appointment.

Length of Call.....