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An observational cohort study of exercise and education for people with chronic obstructive pulmonary disease not meeting criteria for formal pulmonary rehabilitation programmes

A Lewis[1], D Dullaghan[2], H Townes[3], A Green[4], J Potts[1] and Jennifer K Quint[1]

Abstract

Chronic obstructive pulmonary disease (COPD) is a major cause of morbidity and mortality. Pulmonary rehabilitation (PR) is offered to patients with functional breathlessness. However, access to PR is limited. The objective of this study was to evaluate whether a 4-week education and exercise programme offered to COPD patients with Medical Research Council (MRC) dyspnoea 1–2 improves disease self-management. Patients were recruited by their GP to attend four weekly 2-h sessions provided by a multidisciplinary team. Patients completed outcome measures before and after the program. Forty-two patients entered the programme and 26 out of 42 (61.9%) completed all sessions. The Bristol COPD Knowledge Questionnaire and Patient Activation Measure improved (both $p \leq 0.001$). Disease burden was not reduced according to the COPD assessment test. All patients accepted a referral for ongoing exercise. Fourteen current smokers (81.3%) accepted a referral for smoking cessation, three patients with anxiety or depression (37.5%) accepted a psychological therapies referral. The programme improved COPD disease knowledge, patient activation and stimulated referrals to further services supporting disease management. Randomised controlled trials are warranted for similar interventions for COPD patients with early stage disease.

Keywords

COPD, pulmonary rehabilitation, self-management, preventative care, primary care

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Introduction

Chronic obstructive pulmonary disease (COPD) is a major global cause of morbidity and mortality.[1] The gold standard evidence-based intervention for people with COPD who are functionally limited by breathlessness (Medical Research Council Dyspnoea Score of 3 or more) is pulmonary rehabilitation (PR). PR improves COPD patients' quality of life, exercise capacity, muscle strength and dyspnoea. However,

[1] National Heart and Lung Institute, Imperial College London, London, UK
[2] Wandsworth Community Healthcare, Central London Community Healthcare NHS Trust, Battersea Studios, London, UK
[3] Harringey Community Respiratory Team, Whittington Health NHS, Magdala Avenue, London, UK
[4] British Lung Foundation, London, UK

Corresponding author:
Jennifer K Quint, National Heart and Lung Institute, Imperial College London, Emmanuel Kaye Building, 1B Manresa Road, London, SW3 6LR, UK.
Email: j.quint@imperial.ac.uk

access to PR and adherence to programmes remain suboptimal.[2–4] Current referral criteria to enter PR are based on the MRC dyspnoea scale with some PR programmes funded to also include individuals who have had a recent exacerbation requiring hospitalisation. The majority of these individuals will have stable MRC breathlessness levels of three or more. Individuals with an MRC score of 2 should be referred to PR, as it is a British Thoracic Society Quality Standard. However, fewer programmes accept referrals for MRC 2 patients compared to MRC 3–5.[5] Furthermore, according to current UK referral criteria, it is not recommended that patients are referred primarily on the basis of anxiety or depression, which are common in COPD[6,7] and may also be improved with PR.[8]

For individuals with MRC 1–2 breathlessness who are not referred to PR, current recommendations for levels of exercise/physical activity remain the same as for the general population in regard to performing 150 min of moderate intensity endurance activity and strength training at least twice a week. These recommendations may not be appropriate, as COPD patients have greater energy expenditure for activities of daily living compared to healthy controls.[9] The primary healthcare contacts for these patients will be in Primary Care. However, general practitioners' (GPs) knowledge of physical activity guidance is poor.[10]

In addition to exercise, other recommendations for people with COPD who are either early in their disease process or have less severe dyspnoea include smoking cessation, inhaled therapy with bronchodilators and receiving vaccinations for flu and pneumonia. In many other chronic conditions, individuals receive self-management advice close to diagnosis such as in diabetes and chronic heart failure.[11,12] This is not always the case for people with COPD. The evidence for self-management intervention benefit for people with COPD is from those who have more severe disease and symptom burden.[13,14] Therefore, there is currently a gap in self-management evidence and service provision for individuals with COPD with low levels of reported breathlessness and has been identified a priority area of research need recommended by the Chartered Society of Physiotherapy 2017 research priorities. This research aimed to evaluate whether the programme was successful in helping patients to self-manage their condition; as measured by whether their disease knowledge improved and symptoms and disease burden reduced as a result of attending the programme.

Methods

The British Lung Foundation, Whittington Health NHS Trust and University College London Hospitals (UCLH) were commissioned by Islington Clinical Commissioning Group (CCG) to deliver a programme for patients in Islington with COPD with a dyspnoea score of less than 3 on the MRC scale and not experiencing frequent exacerbations. Patients who were experiencing severe exacerbations were eligible for a standard PR programme.

Public and patient involvement

Islington is an urban London Borough with higher levels of deprivation and smoking prevalence compared to the UK national average.[15] Four multidisciplinary COPD workshops were held at the start of 2012 as Islington was starting to develop its integrated care strategy. The workshops welcomed input from patients, commissioners, local public health teams, GPs, practice nurses, consultants and voluntary organisations and sought to review the current pathway and services and understand whether any gaps existed. One key point, brought up by COPD patients during discussions about self-management, was that while there was a well-established PR programme for those patients with MRC of 3 or more in Islington, there was no equivalent programme for patients who are newly diagnosed or who had less severe COPD. Patients felt that a support programme available early on in the course of their disease would have helped them to better understand their condition and possibly prevent or slow their condition from worsening.

Study design and participants

In this 8-month pilot study, 67 participants with COPD and MRC dyspnoea score of 1–2 were recruited. Potential participants were identified by GPs from their registers. GPs contacted patients identified from this register and asked them if they want to take part. Only if individuals agreed were their details then passed on to the research team. Potential patients were also identified when they attended their GP surgery for other reasons or for a COPD annual review.

Inclusion criteria

Any patient registered with an Islington GP with a spirometry and clinician confirmed the diagnosis of COPD and an MRC dyspnoea score of 1 or 2.

Exclusion criteria

People who had significant unstable cardiac or other disease that would make exercise unsafe or prevent programme participation were excluded. People who were unable to walk or whose ability to walk safely and independently was significantly impaired due to non-respiratory-related conditions were also excluded. People unable to participate in a group environment or for whom group sessions were not suitable were excluded, for example, extreme frailty, sight or balance impairment, or for whom mental health, cognitive, personality or other communication barriers that make group work inappropriate. Referral back to the GP occurred if the referral was inappropriate for any of the above reasons.

Outcomes

Individuals who consented to participate were clinically assessed by a senior physiotherapist for entry onto the programme. Participants were asked to complete baseline patient reported outcome measures and repeat these at the end of the programme. At 3 and 6 months post programme, the COPD Assessment Test (CAT) and Patient Activation Measure (PAM) were completed again with a member of staff at the British lung foundation (BLF) over the telephone. Loss of data at follow-up was recorded by the BLF. Patient reported outcome measures included The Bristol COPD Knowledge Questionnaire (BCKQ)[16] to assess patient disease knowledge. The BCKQ is self-administered and comprises of 13 domains. Each domain consists of five statements regarding COPD each answered with a 'true', 'false' or 'don't know'. The CAT was chosen[17] to assess disease burden. This questionnaire comprises of eight questions scored from 0 to 5 on extent to which their disease limits them regarding symptoms and activities of daily living. A score of 40 indicates the greatest disease burden and a score of 5 is the upper limit of normal for 'healthy' smokers. A previously established minimal clinical important difference for PR is between 2 and 3.[18,19] The Hospital Anxiety and Depression scale (HADS)[20] was used to assess anxiety and depression. On the HADS, scores of 8 or more suggest possible anxiety or depression, and scores of 11 or more indicate probable clinically significant disease. A change in score of 1.5 is the minimal clinically important difference (MCID) for the HAD.[21] The PAM[22] was used to assess how engaged and knowledgeable individuals were with their healthcare and self-management. It consists of 13 items with overall scoring from 0 to 100. The higher the score, the greater the disease knowledge and confidence to manage a health condition. Feasibility outcomes included patient attendance and satisfaction with the programme and the extent to which the programme stimulated ongoing referrals to other community services. The primary outcome measure piloted was the PAM. Participants were asked to answer a patient satisfaction questionnaire at the end of the programme (Appendix 1).

Ethics

This study was approved by London – Harrow research ethics committee (REC no: 14/LO/1355)

The programme

Participants attended four weekly programme sessions in the evening lasting 2 h. These sessions were supervised by a senior physiotherapist and rehabilitation assistant. Other Allied Health Professional, nursing and medical colleagues contributed to the education component of the programme. Each session consisted of a brief introduction, education component, at least 45 min of exercise intervention and a closing debrief and planning period. Full details of the programme can be found in Figure 1:

All clinicians running the programme completed The Advanced Development Programme (ADP). The ADP trains healthcare professionals in strategies and skills to support people with long-term conditions to optimally self-manage using the principles of collaborative agenda setting, goal setting and action planning and goal follow-up. These principles are based on the Chronic Care Model theory.[23]

During aerobic exercise, patients were asked to try to become moderately or somewhat severely breathless using the Modified Borg Dyspnoea scale. During resistance exercises, patients were encouraged to gradually progress the weight or the number of sets performed according to being able to achieve the correct technique without reaching repetition failure for a consecutive week. The aim of the exercise programme was not to alter the physiology of the patient over four sessions. It was to increase the patient's knowledge regarding the importance of exercise to reduce progression of their condition and to increase their confidence exercising.

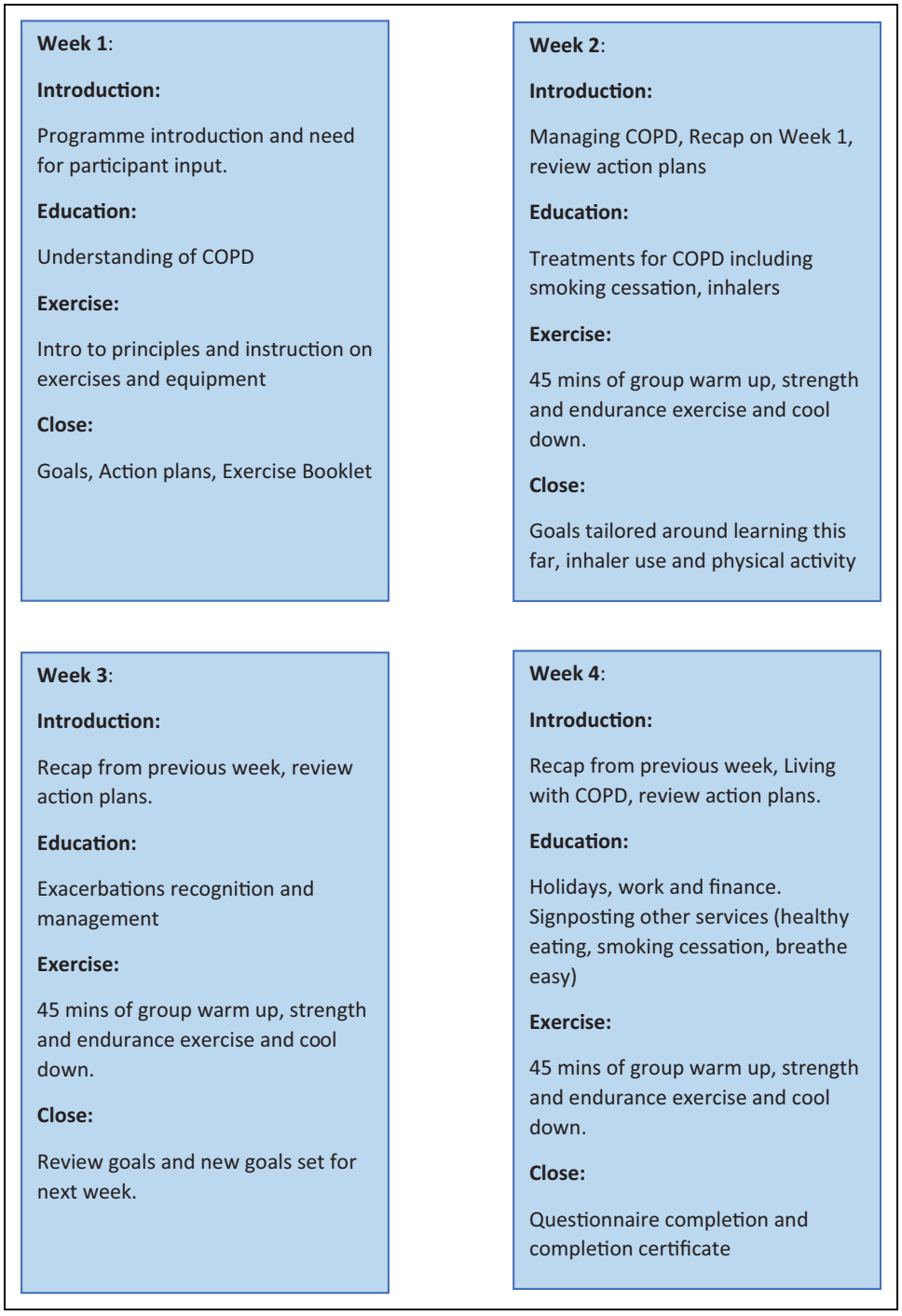

Figure 1. Weekly session content.

Statistical analysis

Statistical analysis was performed using STATA 15. Change following participation in the programme was evaluated for categorical/ordinal grouped data and non-normally distributed data using the Wilcoxon rank test. Continuous normally distributed paired data were analysed using a two-tailed paired *t* test. The level of significance was set at $p < 0.05$. Data were analysed by research team members with no involvement in research participant clinical care to reduce bias. Missing data at follow-up are acknowledged in the results tables where paired measurements alter between outcomes.

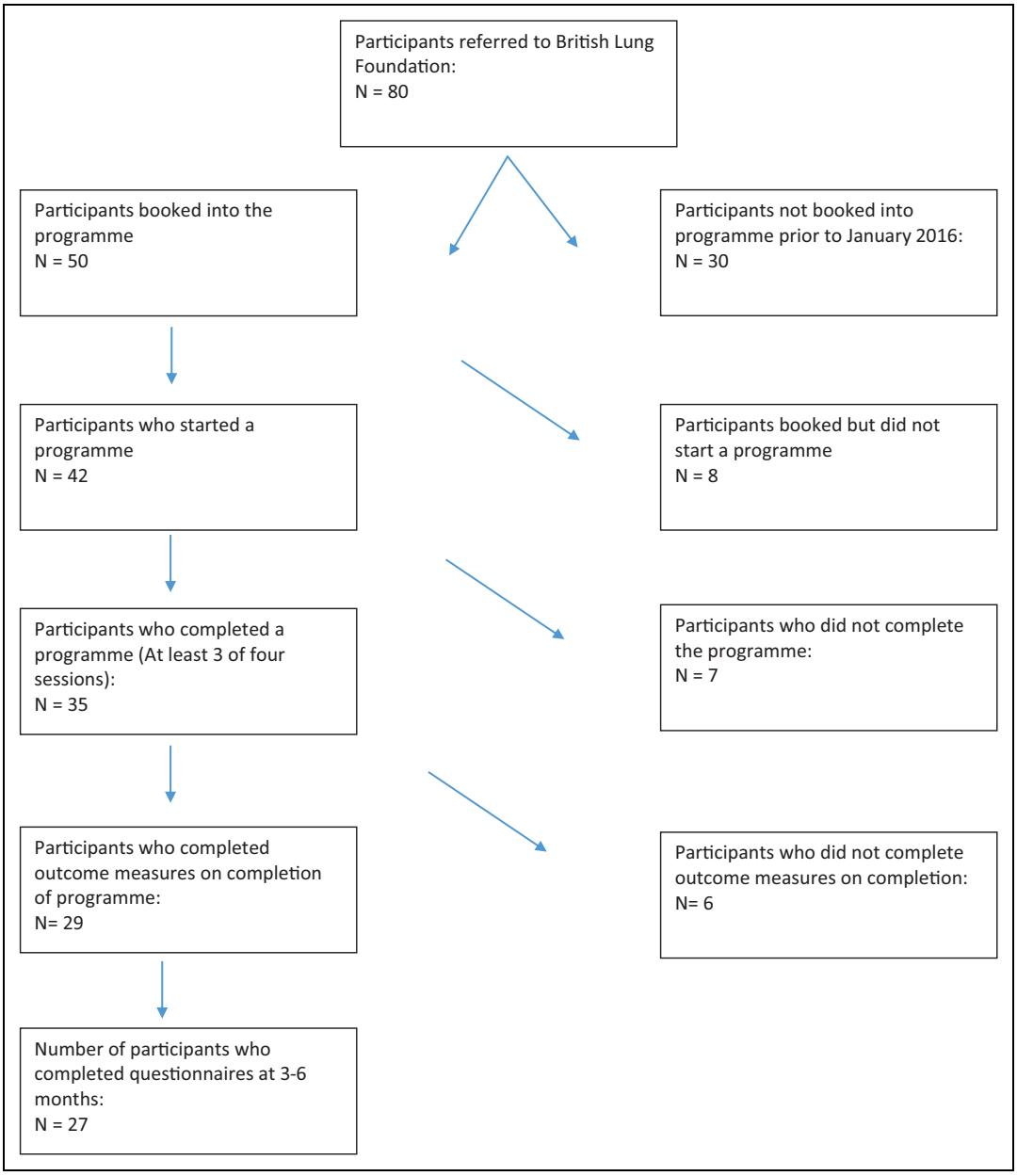

Figure 2. Patient flow diagram.

Results

Baseline demographics

Eighty referrals were received by the BLF from GP's. Thirty participants were not booked into a programme. Participant reported reasons for not being booked to start a programme include being too busy,[1] did not receive information,[1] language difficulties,[1] no answer on the phone,[3] new carer responsibilities,[1] class cancelled due to low numbers,[15] no diagnosis of COPD,[1] no reason stated,[3] work commitments[3] and timing inappropriate.[1] Eight were booked to start but did not participate further without further information available on reasons why. Therefore, 42 participants entered the programme (Figure 2). Recruitment was targeted from practices with high numbers of COPD patients with MRC 1–2. However, it is not known how many eligible patients were approached by GPs, and how many individuals declined a referral to the programme. Participants had a mean age of 62 at recruitment. Participants had moderate COPD and the majority (57.1%) was ex-smokers. Patient activation levels were low, and they had poor knowledge about their condition. Baseline demographics are presented in Table 1.

Table 1. Baseline demographics of participants in the programme.[a]

Baseline characteristic	Mean (SD/%)
Age ($n = 67$)	62 (11.4)
Sex (F) ($n = 78$)	46 (59%)
Time since diagnosis (years) (n=35)	2.4 (2.7)
FEV1%Pred ($n = 28$)	59.8 (23.9)
BMI ($n = 40$)	24.6 (4.8)
Smoking status ($n = 63$)	
Never smoker	1 (1.6)
Ex-smoker	36 (57.1)
Current smoker	26 (41.3)
BCKQ ($n = 52$)	29.9 (8.4)
CAT ($n = 50$)	18.3 (7.9)
PAM ($n = 50$)	38.1 (4.4)
HADS-A ($n = 50$)	7.5 (4.9)
HADS-D ($n = 50$)	6.3 (4.3)

BCKQ: Bristol COPD knowledge questionnaire; CAT: Chronic Obstructive Pulmonary Disease Assessment Test; PAM: Patient Activation Measure; HADS-A: Hospital Anxiety and Depression Scale Anxiety subdomain; HADS-D: Hospital Anxiety and Depression Scale Depression subdomain; FEV1%Pred: Forced Expiratory volume in 1 second percent predicted; BMI: Body Mass Index.

[a]*n* represents the total number of participants who provided this data at baseline from referral or questionnaire completion.

Changes in outcomes following the COPE programme

Thirty-five (83.3%) of the 42 participants who entered the programme attended three of four sessions and were classified as 'completers'. The reasons for seven participants not being able to attend the last session included work commitments,[2] family reasons[2] and having another appointment at the same time[1] or no reason given.[2] No participants changed smoking status as a result of completing the programme. However, 14 (81.3%) current smokers agreed to be referred to a smoking cessation service. Baseline HADS scores were clinically significant in eight participants, three (37.5%) of whom accepted a referral to a local Increasing Access to Psychological Therapies (IAPT) service. Twenty-six (100%) accepted a referral to an ongoing exercise programme. Reasons for non-completion or attendance were varied. Timing of the classes, work commitments, carer responsibilities, problems with parking and inability to attend during school holidays were reasons given. No adverse events were reported by participants. Twenty-one participants (77.8%) were followed up at 3 months. Six participants (22.2%) could not be contacted at 3 months post completion but were contacted at 6 months post completion. Outcome changes from before and after the programme are presented in Table 2.

When participants were telephoned by someone from the BLF at 3 months post programme completion, one participant had quit smoking and seven participants had started or completed an exercise on referral scheme. At 6 months, a further three participants had quit smoking and a further two participants had started or completed exercise on prescription.

Patient satisfaction questionnaire data

Twenty-five individuals completed and returned the patient satisfaction questionnaire at the end of the programme. Regarding ratings about the venue, 82 out of 119 (68.9%) returned answers rating the venue as excellent with only one answering 'poor' (0.8%). Table 3 illustrates other service ratings.

Participants reported that the programme acted as a stimulus to stop smoking and maintain exercise:

> This service let me understand better my condition . . . made me realise how important it is for me to stop smoking. (P16)

> I have become an expert about COPD, found it very interesting. Since been to Whittington to stop smoking. (P6)

> I also found the gym very useful as it has taught us exercise doesn't need to end. (P4)

The knowledge gained about COPD seemed to be most useful for participants, especially when living with early stage COPD:

> Helpful to have a mix of information, questions answered, practical advice and experience of the gym. Particularly helpful to have this at an early stage of COPD. Also the links to local activities and exercise by referral. (P3)

> I didn't know much about COPD. Useful to know I can exercise and not worry about breathlessness. So that helps me be more determined to stop smoking. (P16)

> Clear information, clear question and answers, Exercise information. Clear information on local groups and centres for exercise. (P21)

Individuals had negative comments about the programme. The component that was perceived as least useful was the smoking cessation advice for some

Table 2. Outcome measure changes from completers of the programme.[a]

	Pre who have post	Post (4 weeks)	Change	*p* Value (significance < 0.05)
Smoking status	(*n*%)	(*n*%)	(*n*%)	
Never smoker *N* (paired) = 1	1 (2.7)	1 (2.7)	0 (0%)	$p = 1.0$
Ex-smoker *N* (paired) = 20	20 (54.0)	20 (54.0)	0 (0%)	
Current smoker *N* (paired) = 16	16 (43.2)	16 (43.2)	0 (0%)	
	Mean (SD)	Mean (SD)	Mean change (95% CI)	
BCKQ *N* (paired) = 38	29.5 (8.3)	43.4 (7.8)	13.9 (11.2–16.6)	$p < 0.001$
CAT *N* (paired) = 38	18.7 (8.2)	18.3 (8.7)	−0.4 (−2.5–1.7)	$p = 0.7$
PAM *N* (paired) = 30	38.0 (4.2)	42.1 (5.6)	4.1 (1.7–6.4)	$p = 0.001$
HADS-A *N* = 50				
HADS-D *N* = 50				

BCKQ: Bristol COPD Knowledge Questionnaire; CAT: Chronic Obstructive Pulmonary Disease Assessment Test; PAM: Patient Activation Measure; HADS-A: Hospital Anxiety and Depression Scale Anxiety subdomain; HADS-D: Hospital Anxiety and Depression Scale Depression subdomain.
[a]Post PAM is at 3 months.

Table 3. Patient satisfaction questionnaire scores.[a]

	Very	somewhat	Not
How satisfied have you been with this service?	24	1	0
Do you feel attending this exercise class has improved your knowledge of COPD?	24	1	0
Do you feel more confident managing your COPD?	24	1	0
Do you feel you have an increased knowledge about the importance of exercise?	25	0	0
Do you feel you have gained increased knowledge in how to maintain an active lifestyle?	24	1	0

[a]Individuals gave general comments on their satisfaction with the programme: what was most useful, least useful and suggestions for the future.

who had already stopped but helpful suggestions were made:

> Smoking session: I have not smoked for at least 25 years. If you have a larger group you might consider an alternative activity for the non-smokers. (P3)

Individuals gave support for the service and valued the 'expert patient' interaction:

> It should be compulsory for all COPD sufferers to come to these classes to learn to understand what this disease is and what you can do to help yourself. (P1)
>
> Please keep this ongoing. Don't cut this service. (P6)
>
> (name) came to talk us about his health problems, was a delight to listen to. He was very reassuring about taking my medications. (P7)
>
> I do hope this programme continues. It showed that people need to talk about their diagnosis. It was extremely helpful and I learnt a lot. Although I gave up smoking years ago, I think longer or more sessions on that would be useful as everyone seemed to want to talk about that. (P15)

Discussion

Summary of main findings

The programme is a structured 4-week programme of education and exercise for people with COPD and MRC dyspnoea 1–2. The programme enabled participants to improve their knowledge and activation levels regarding their health condition. The programme acted as a stimulus for behaviour change with participants accepting referrals to smoking cessation, psychological therapies and ongoing exercise schemes.

All patients accepted a referral to ongoing exercise schemes. This may be a result of the type of individual attracted to the research study. Nevertheless, all participants were eligible for referral to such schemes already through their GP but were not participating in such a scheme. Therefore, the programme may improve access to an underutilised Primary Care resources. Individuals with less breathlessness

compared to those referred to standard PR programmes may have greater self-efficacy towards exercise. Should exercise and physical activity be maintained early in COPD, this may impact on disease progression and mortality. For example, quadriceps strength predicts mortality in COPD.[24]

The majority (81.3%) of current smokers accepted a referral to smoking cessation programmes. The content of the education provided, combined with the findings of the patient satisfaction questionnaire, indicate that smoking cessation advice was a core element of the programme and acknowledgement was made of the need to stop smoking because of increased disease knowledge as described by participants in their qualitative feedback.

The mean time since participant diagnosis of COPD in this study was 2.4 years. Therefore, individuals may be classified as newly diagnosed. Fischer et al.[25] report those COPD patients who had been diagnosed for 5 years or more had a greater belief that their symptoms were due to COPD, perceived greater consequences, perceived that their COPD would disable them for longer and were less optimistic about disease controllability. Furthermore, Lewis et al.[26] state that living with uncertainty about COPD was disabling for patients who had not yet received PR, making some feel like they were deteriorating living with the condition, experiencing fear, panic and an awareness of being close to death. Interventions such as the programme offered close to diagnosis may enable disease perceptions and resulting behaviour change to occur more successfully than waiting till patients are eligible for PR, sometimes years after diagnosis.

The BCKQ significantly improved as a result of the programme. This reflects the patient satisfaction findings. There is a paucity of data on the responsiveness to change in the BCKQ from self-management or PR interventions. White et al.[16] reported that participants attending an 8-week bi-weekly PR programme increased their BCKQ score by 18.3% compared to the 20.7% in this study. These figures are similar which validates the structure and delivery of the programme education, supports the didactic approach chosen and may be replicated in further studies and clinical practice. Furthermore, this is encouraging considering participants received a third of education sessions compared to traditional PR programmes.

The PAM score improved after the programme, suggesting that the programme provides an environment where individuals can modify their health-seeking behaviour, although the average post programme figure of 41.8 indicates that this sample remained in the lowest level of activation towards their health. This level of activation means that participants were disengaged and overwhelmed by their respiratory disease. For comparison, the mean PAM score of 4339 patients with COPD from an international survey including UK patients was 66.75, and the majority of participants had the highest level of activation, meaning they had confidence and knowledge to manage their condition, whereas only 15% had the lowest level of activation.[27] Of note, participants in the programme had low activation even though all accepted a referral for ongoing exercise and the majority for smoking cessation. The improvement in PAM score with the programme was less than that seen from PR, where a UK study found an improvement of 7.52, from 54.91 points at baseline.[28]

There were no significant improvements in respiratory related health quality of life following the programme. The MCID in CAT score is established for PR and estimated between 2 and 3.[19,29] PR is normally delivered at least twice weekly and run for at least 6 weeks.[30] There may be a lacking dose response in the programme to illicit significant reduction in disease burden.

How and why it agrees or disagrees with the existing literature

Other self-management strategies have been trialled in the United Kingdom incorporating education and exercise for individuals with COPD and MRC dyspnoea 2.[31,32] However, neither the 'SPACE for COPD' trial or 'my-PR' trial included MRC dyspnoea score 1 patients. Nevertheless, the education and exercise recommendations provided across trials, within the same healthcare climate, allow for comparisons to be drawn. The 'my-PR' online programme of PR support achieved a mean difference reduction of 2.9 points in the CAT score and the 'SPACE for COPD' achieved significant improvements in CRQ-SR domains of dyspnoea, fatigue and emotion, but not mastery. Overall CRQ-SR scores were not presented. Both trials also lasted for longer periods of between 6 and 7 weeks compared to the programme, and our study may not have been achieved a significant dose-response. The SPACE for COPD programme also administered the BCKQ before and after their 6-week intervention. There was a mean improvement of 2.79 points compared with 13.9 points in our study.

This may highlight the benefits of face-to-face education and the ability to ask questions. It may also suggest that COPD patients may be more amenable to behaviour change at a point closer to diagnosis with milder disease burden, because they are less likely to consider their condition a chronic illness.[25] The 'SPACE for COPD' also had favourable rates of participant smoking cessation at 6-month follow up compared to usual care. Our findings also indicate that holistic self-management interventions in individuals with MRC of less than 3 stimulate behaviour change and therefore may alter disease progression in the long term.

Strengths and the limitations of this study

There was no control group included in this study. Our results indicate that further randomised controlled trials are indicated for self-management support with individuals with COPD and MRC breathlessness scores of 1–2.

There were no functional/exercise capacity measures, and limited spirometric measurements available from referral to the programme. These data relied on the quality of GP administration of the referral. This limits interpretation of the results in comparison with other studies. Such endpoints are recommended for future trials.

There are missing data at follow-up. This is common in PR when participant drop out indicates that they do not return for a final assessment and participants had the right to withdraw from this study without giving reason and so this is hard to control for. Future studies using these outcomes should distribute all patient reported outcome measures at baseline, 4 weeks, 3 and 6 months.

Implications for future research or clinical practice

To the authors' knowledge, the programme is the first of its kind to be researched in the United Kingdom and needed a benchmark from which to do further research. Randomised controlled trials of similar self-management interventions are warranted prior to such programmes being included in practice-based guidelines. This pilot study suggests that using the BCKQ and PAM are useful outcome measures to detect change in disease knowledge and patient activation. Furthermore, it is recommended that future trials should record participant uptake of other services such as exercise referral schemes as a measure of successful long-term activation and engagement in healthcare that could potentially modify the course of disease progression.

Conclusion

The programme of education and exercise is an effective approach to improve disease knowledge and activation of individuals with COPD and MRC dyspnoea scores of 1–2. The programme also may promote behavioural change by stimulating referrals to smoking cessation services, psychological therapies and exercise schemes. These activities may prevent disease progression and be particularly effective if provided close to diagnosis. Further randomised controlled trials of self-management interventions for COPD patients not eligible for PR are warranted.

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ORCID iD

A Lewis https://orcid.org/0000-0002-0576-8823

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Appendix 1

The COPE programme satisfaction questionnaire

Date_____

Q1: Where are you attending the COPE programme?:

	a) Excellent	b) Good	c) Fair	d) Poor
Location				
Space				
Temperature				
Toilet facilities				
Cleanliness				

Q2: Venue rating
Q3: How satisfied have you been with this service?

a) Very satisfied ☐ b) Satisfied ☐ c) Not satisfied ☐

Comments:

_____
_____
_____

Q4: Do you feel attending this exercise class has improved your knowledge of COPD?

a) Very much ☐ b) Somewhat ☐ c) Not at all ☐

Q5: Do you feel more confident managing your COPD?

a) Very much ☐ b) Somewhat ☐ c) Not at all ☐

Q6: Do you feel you have an increased knowledge about the importance of exercise?

a) Very much ☐ b) Somewhat ☐ c) Not at all ☐

Q7: Do you feel you have gained increased knowledge in how to maintain an active lifestyle?

a) Very much ☐ b)Somewhat ☐ c) Not at all ☐

Q8: What did you find the most useful part of the programme?

Comments:

_____
_____
_____
_____
_____

Q9: What did you find the least useful part of the programme?

Comments:

_____
_____
_____
_____
_____

Q12: Any other comments or suggestions?

_____
_____
_____
_____
_____

Thank you for taking the time to complete this survey.