

Helping you help yourself for patients with COPD and mild breathlessness: A service evaluation in Wales

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Abstract

Background

Pulmonary rehabilitation (PR) is an evidence-based intervention which improves exercise capacity and quality of life (QoL) for patients with chronic obstructive pulmonary disease (COPD). Commonly, outpatient rehabilitation is available for patients with significant breathlessness (Medical Research Council (MRC) >3). This evaluation explored changes in exercise capacity and knowledge of condition and their relationship with the impact of COPD (CAT score) at baseline following a community exercise and education programme delivered by the British Lung Foundation (BLF) in people with mild breathlessness (MRC ≤2).

Methods

People with mild breathlessness, MRC ≤2, were recruited from GP surgeries, the BLF website and support groups. The 6-week *Helping you help yourself (HYHY)* programme included weekly exercise, education and social engagement. Participants were assessed at baseline using the COPD Assessment Tool (CAT), 6-minute walk test (6MWT), Bristol COPD Knowledge quiz (BKQ), and questions on self-management was assessed by questionnaire. After 6 weeks 6MWT, BKQ and self-management were assessed and related to CAT at baseline. The usefulness of the programme to participants was also assessed by questionnaire.

Results

In the 210 patients who completed assessments before and after **rehabilitation**, there was an increase in 6MWT distance, median (IQR) 60 (30–80)m and

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BKQ 3 (1–4) points ($p = <0.05$), and most elements of self-management improved. Almost all participants considered HYHY useful ($p = <0.05$). There was no relationship between baseline CAT score and change in outcome measures ($p = >0.05$).

Conclusion

The results support the provision of community rehabilitation as an alternative to hospital-based interventions to support and promote self-management in people with mild breathlessness across the severity of disease burden as measured by CAT.

Introduction

Pulmonary rehabilitation (PR) is an evidence-based intervention which improves exercise capacity and quality of life (QoL) for people with chronic obstructive pulmonary disease (COPD). One of the aims of PR is to promote behaviour change to enhance healthy behaviours, such as physical activity and self-management beyond the short-term programme provided. Typically, in the United Kingdom (UK) rehabilitation is recommended for patients with significant breathlessness as measured by Medical Research Council (MRC) 3–5 (Bolton et al. 2013). However, this results in limited accessibility for patients with mild symptoms. Maintaining healthy lifestyles beyond the rehabilitation setting remains a challenge. The reasons are multifactorial and include the impact of breathlessness on exercise tolerance and difficulties integrating into standard community exercise provision (Hogg et al. 2012).

It has been acknowledged that increased access to PR is needed which may be achieved by increasing community-based programmes including developing and validating novel models to deliver sustainable PR, promoting maintenance of long-term results, and identifying those who should be prioritised (Vogiatzis et al. 2016). It is suggested that positive behaviour changes and healthy choices at the early stages of COPD can help slow down the disease progression (Jolly et al. 2018). Evidence from a systematic review (including 3 studies) highlighted the benefits of PR for mild COPD ($FEV_1 \geq 80\%$ predicted) with improved exercise capacity and QoL. However, FEV_1 is a relatively poor correlate of symptoms such as breathlessness and the impact of COPD on daily life and therefore investigating the impact of people with mild breathlessness is needed (Jones et al. 2012). Community-based rehabilitation for mild breathless may provide an opportunity for early lifestyle modification, self-management and physical activity before breathlessness becomes disabling with reduced cost to healthcare services (Golmohammadi et al. 2004) and there is evidence that a twice weekly community rehabilitation programme can improve exercise tolerance

and QoL (Cecins et al. 2017). In response, BLF Wales set up a low resource 6-week community-based exercise and education programme, based on PR guidelines: *Helping you help yourself*. A similar programme of weekly exercise and education for 4 weeks in England showed improvements in exercise capacity and knowledge of disease and self-management (Lewis et al. 2019).

The aim of this evaluation was to gain information on the demographics of people with self-reported COPD (in the absence of spirometry) with mild breathlessness that are attending the HYHY programme in Wales and to investigate changes in exercise capacity, knowledge of COPD and self-management behaviours as a result of the programme. In addition, relationships with the impact of respiratory disease COPD Assessment Test (CAT) score at baseline were explored. It was hypothesised that there would be significant differences in 6-minute walk test (6MWT) distance and knowledge of condition with HYHY, and that participants would gain benefit irrespective of CAT score. The usefulness of the programme to participants was also evaluated.

Methods

Study design

This was a retrospective evaluation of the BLF *Helping you help yourself* programme funded by the National Community Fund Wales. HYHY involves weekly exercise, education and social engagement across three health boards in South Wales. Recruitment and data collection were managed by the BLF, participants were recruited from GP surgeries and through the BLF website and *Breathe easy* groups.

Inclusion/exclusion criteria

People with self-reported COPD and mild breathlessness, as determined by the MRC breathlessness scale of ≤ 2 (where 5 is most breathless), who live or work in Wales were eligible for the study. People with MRC > 2 , blood pressure $> 190/100$ mmHg, Borg resting breathlessness > 5 , and resting oxygen saturations $SpO_2 < 85\%$ as well as those living outside Wales were excluded.

HYHY programme

HYHY ran between March 2018 and March 2020. The programme was once a week for 6 weeks, each class was undertaken in a community setting (local community hall/leisure centre) for approximately 2 hours per week as a low resource intervention. A typical session included 30–40 minutes exercise plus a 10-minute warm up and cool down, 30 minutes of education and 30 minutes for (optional) social engagement. The exercise was led by a level 4 chronic respiratory disease trained programme coordinator and included: aerobic and strength training modified weekly by the programme coordinator and aiming for a ‘somewhat hard’ rate of perceived exertion (rate of perceived exertion 13/14).

Standardised education provided by healthcare professionals (such as respiratory nurses, physiotherapists, occupational therapists and pharmacists) based on motivational

interviewing techniques (Rollnick & Miller 1995). The programme builds on the learning of BLF self-management programmes elsewhere in the UK and included the following topics: understanding COPD and self-management, managing breathlessness, being active, managing flare ups and medications, looking after yourself and further support. People attending HYHY were also provided with the BLF *Your COPD self-management plan* and *Your exercise handbook* booklets, which were referred to during the education sessions. The BLF provided information about HYHY to potential participants and obtained consent from all participants. The BLF gave permission for the use of the retrospective anonymous data and ethical approval was gained from the School of Healthcare Sciences at Cardiff University in July 2019.

Assessments

Participants were asked to confirm MRC breathlessness for recruitment to the service, but scores were not recorded for the analysis. Assessments were collected by the exercise instructor and included age (by category), gender and body mass index (BMI) and resting blood pressure of participants were recorded as well as self-reported smoking history, number of GP appointments and hospital admissions in the past 6 months at baseline. The CAT score is a COPD specific measure of the impact of the disease and is valid and reliable in COPD. It consists of eight-topic domains, each is presented as a 6-point scale (0–5) reflecting impact of symptoms, including cough, phlegm, chest tightness, breathlessness; limitations; confidence leaving home; sleep and energy. The total score ranges 0–40, with a higher score representing greater impact of COPD (Jones et al. 2009). CAT was measured at baseline only as it has previously been shown to be response to PR (Dodd et al. 2011).

Assessments before and after HYHY included the following (Table 1):

Table 1: Assessment schedule.

	Baseline	After 6 weeks
Demographic data	X	
6-minute walk test	X	X
Bristol knowledge quiz	X	X
Self-management behaviour	X	X
COPD assessment tool score	X	

6-minute walk test (6MWT), a sub-maximal exercise test used to assess aerobic capacity and endurance, was performed on a 10m track (without a practice test) before and after 6-weeks of HYHY programme. The validity and reliability of the test has been shown previously (Singh et al. 2014). Pre and post 6MWT measures of breathlessness (Borg 0–9 a valid measure in PR (Crisafulli & Clini 2010) and oxygen saturation were taken using pulse oximetry.

Knowledge, impact of COPD and self-management behaviours were assessed by self-administered questionnaires before the start of the exercise programme (visit 1), 6 weeks (visit 2) and 6 months after the programme (visit 3 by telephone).

A sample of 12 questions (*Bristol knowledge quiz: BKQ*) from the *Bristol COPD knowledge questionnaire* (BCKQ) (excluding COPD aetiology which was of limited relevance) were completed. Each question has 3 response options *true*, *false*, and *don't know*. A correct answer scores 1 point, while an incorrect answer or *don't know* scores 0. Thus, BKQ scores ranged from 0 to 12, high scores indicating greater knowledge. The BCKQ is an instrument that assesses knowledge of COPD in 13 areas: COPD epidemiology, breathlessness, phlegm, chest infections, exercise, smoking, vaccination, bronchodilators, antibiotics, oral and inhaled steroids (White et al. 2006).

To assess self-management behaviours an unvalidated tool was used, with participants asked to rate their agreement on a 5-point Likert scale to 9 statements including: understanding of condition, where to find further information about managing their lung condition, what to do during a flare-up, smoking status, healthy eating, importance of exercise, social life, happy with social network and attending social activities ([Appendix 1](#)).

Data were analysed using SPSS version 25, normality was tested using Kolmogorov-Smirnov test and assessed visually looking at the distribution according to the histogram outputs. As data were not parametric, median and interquartile range (IQR) are presented. Independent groups (included and excluded data) was compared with the Wilcoxon test for paired analysis. Group proportions were compared using Chi square test, and the Spearman's rank correlation was used to look for relationships between variables.

Results

Demographic and baseline data

Data from 293 (48% male) participants who commenced HYHY between March 2018 and March 2020 were included in the present analysis. The majority were aged above 65 ($n = 230$), $n = 55$ were aged 55–64, $n = 7$ aged 45–54 and $n = 2$ aged 35–44 and $n = 1$ aged 23–34 years. There were 45 smokers, 224 non-smokers and 24 declined to say.

Of the 293 who started HYHY, 54 failed to complete (28%) the programme and 29 were excluded (15%) due to incomplete data leaving 210 participants who were included in the present analysis. There was no difference in gender, BMI, blood pressure, oxygen or BKQ, smoking status, number of GP and hospital visits between included and excluded data $p = >0.05$ (Table 2).

Table 2: Participant characteristics for included and excluded data.

	Included data <i>n</i> = 210	Excluded data <i>n</i> = 83	<i>p</i> =
Gender male <i>n</i> = [%]	103 [49%]	37 [45%]	0.490
Age 25–34 years <i>n</i> =	0	1	0.037
35–44 years <i>n</i> =	0	1	
45–54 years <i>n</i> =	4	3	
55–64 years <i>n</i> =	33	22	
65+ years <i>n</i> =	173	56	
Height (m)*	1.7 (1.6–1.7)	1.7(1.6–1.8)	0.634
Weight (kg)	78.0 (67.8–93.3)	81.0 (69.0–92.0)	0.665
BMI (kg/m ²)*	28.2 (24.8–32.9)	28.1 (25.4–33.1)	0.798
Systolic BP (mmHg)	143 (132–155)	139 (128–152)	0.140
Diastolic BP (mmHg)	82 (74–88)	84 (77–92)	0.188
6 Minute Walk Test distance (m)	340 (268–380)	320 (260–350)	0.033
Oxygen level at rest (%)	96 (95–98)	97 (95–98)	0.307
Breathlessness at rest (1–10)	0 (0–1)	1 (0–1)	0.029
Baseline CAT total (0–40)	18 (13–24)	23 (17–27)	<0.001
Baseline BKQ total (0–12)	3 (4–6)	3 (4–5)	0.696
Smoker <i>n</i> =	30 [15%]	15 [19%]	0.145
Nonsmoker <i>n</i> =	164 [84%]	60 [77%]	
Neither <i>n</i> =	2 [1%]	1 [1%]	

Data are Median (IQR) *missing data (complete *n* = 196, non-complete *n* = 78); BP: blood pressure, BKQ: Bristol COPD knowledge quiz, CAT: COPD assessment tool.

There was a significant difference in age between completers and non-completers with a higher proportion of older people with complete data (*p* = 0.037). Breathlessness at rest (Borg) and CAT scores were higher in non-completers and 6MWT was lower than completers (*p* < 0.05). The majority of participants at baseline had no GP or hospital appointments (Table 3).

Table 3: GP and hospital appointments for included and excluded data.

Number of GP appointments	Included data	Excluded data	Number of hospital appointments	Included data	Excluded data
0	79	24	0	198	75
1	46	25	1	6	5
2	40	15	2	4	2
3	25	9	3	1	1
4	20	10	-	-	-
<i>Total</i>	209	83	<i>Total</i>	209	83
Difference included and excluded data	$p = 0.494$		$p = 0.528$		

Self-management

There was no significant difference in any of the questions on self-management in those who completed or did not complete HYHY (>0.05) (data not shown).

Comparison of baseline and post HYHY data

In the 210 participants who completed assessments at baseline and after 6 weeks of HYHY, there was a significant increase in 6MWT median (IQR) 60 (30–80)m and BKQ 3 (1–4) points ($p < 0.05$), and there was no difference in oxygen saturation or breathlessness before or after the 6MWT (Table 4).

Table 4: Change in 6MWT and BKQ with HYHY.

	Baseline	6 weeks post HYHY	$p =$
Distance walked (m)	340 (268–380)	400 (320–440)	<0.001
Oxygen level at rest (%) [*]	96 (95–98)	96 (95–98)	0.667
Oxygen level post 6MWT (%) ^{**}	96 (94–98)	96 (93–97)	0.111
Breathlessness at rest (1–10)	0 (0–1)	0 (0–1)	0.249
Breathlessness post 6MWT (1–10)	2 (1–3)	2 (1–3)	0.310
BKQ total	4 (3–6)	7 (6–9)	<0.001

Data are median (IQR) $n = 210$ unless ^{*} $n = 197$; ^{**} $n = 19$; BKQ: Bristol COPD knowledge quiz.

Self-management

The questions relating to self-management showed significant changes of knowledge of finding further information, knowledge of what to do during a flare up, not smoking and healthy eating, happy with social life, having a network of friends and attending interest groups ($p < 0.05$) (Figures 1–3). Overall participants showed increased knowledge relating to self-management.

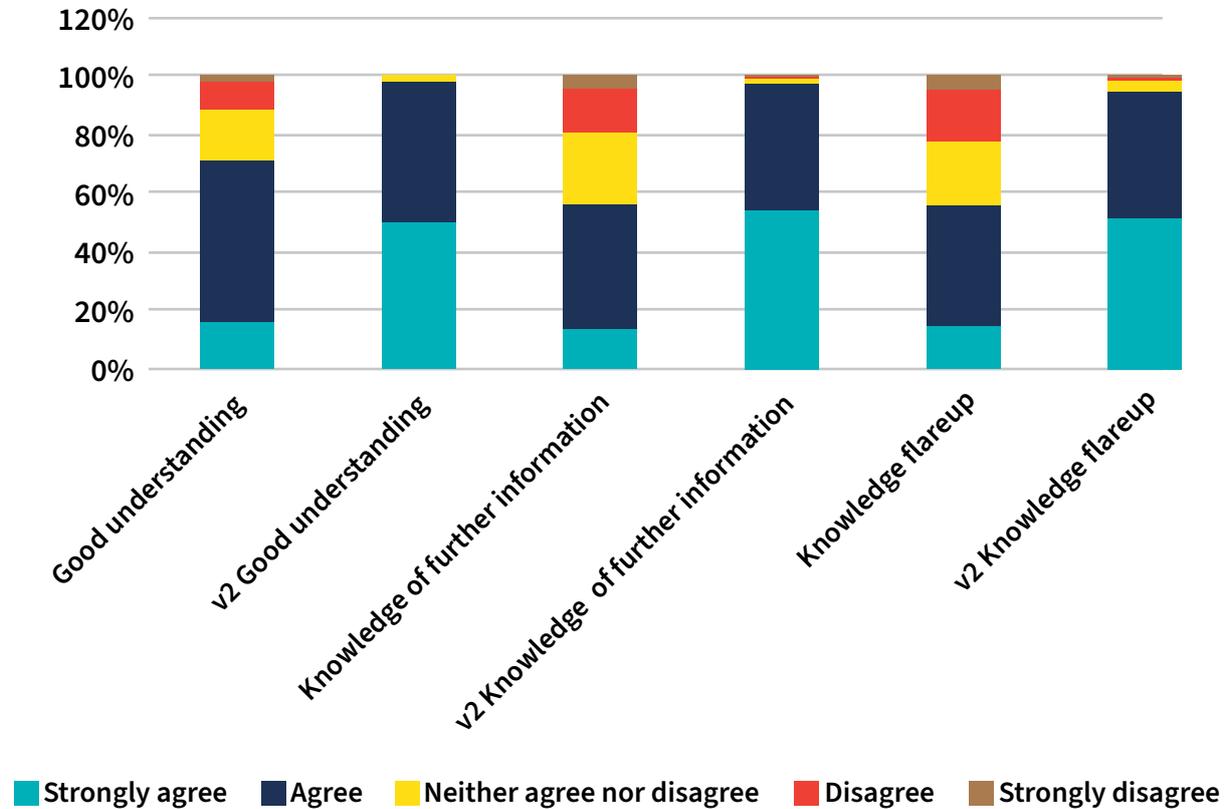
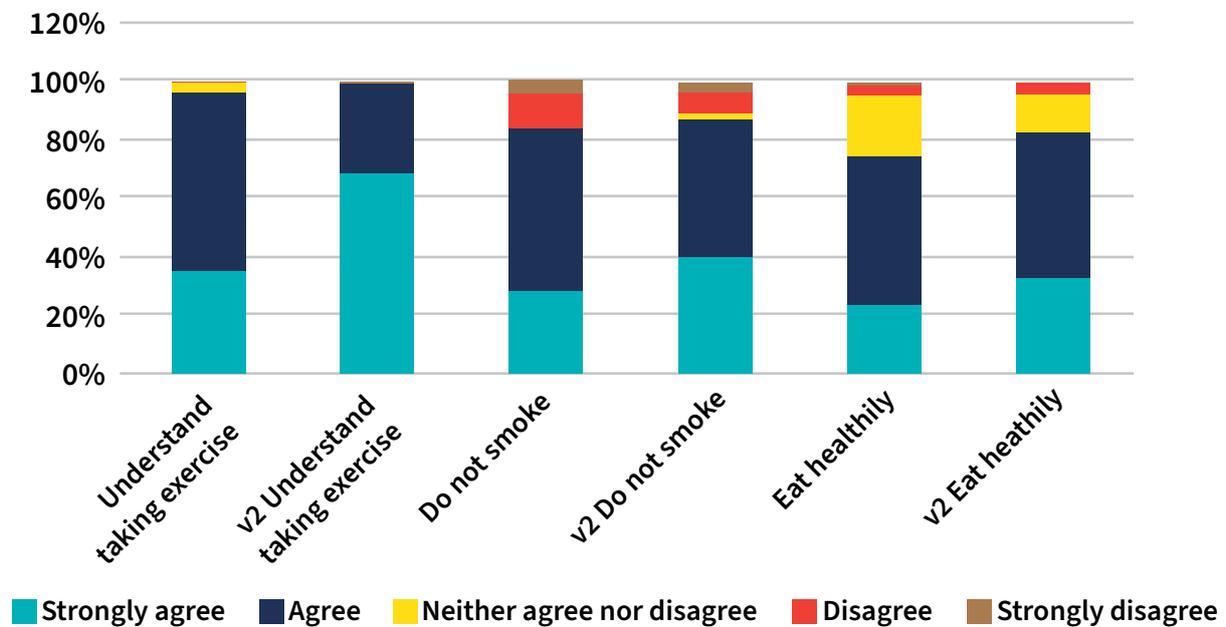


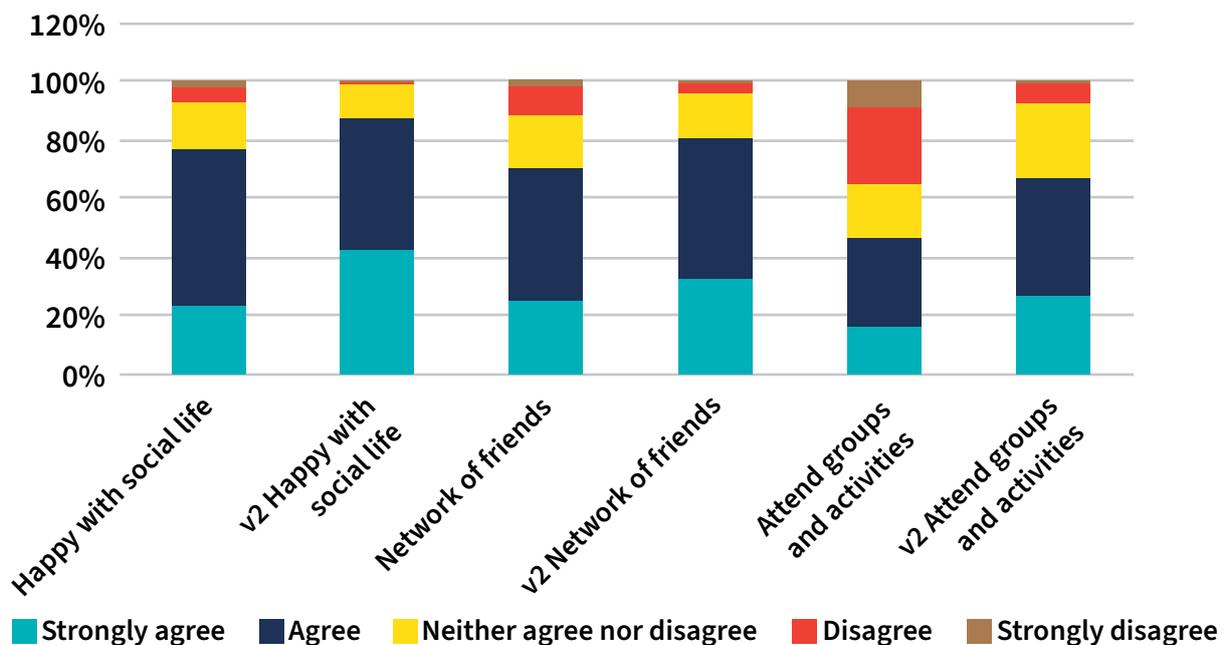
Figure 1: Knowledge of self-management response percentage baseline and after 6-weeks (v2).

* significant difference $p < 0.05$



📌 **Figure 2: Healthy behaviours response percentage and after 6 weeks (v2).**

* significant difference $p < 0.05$

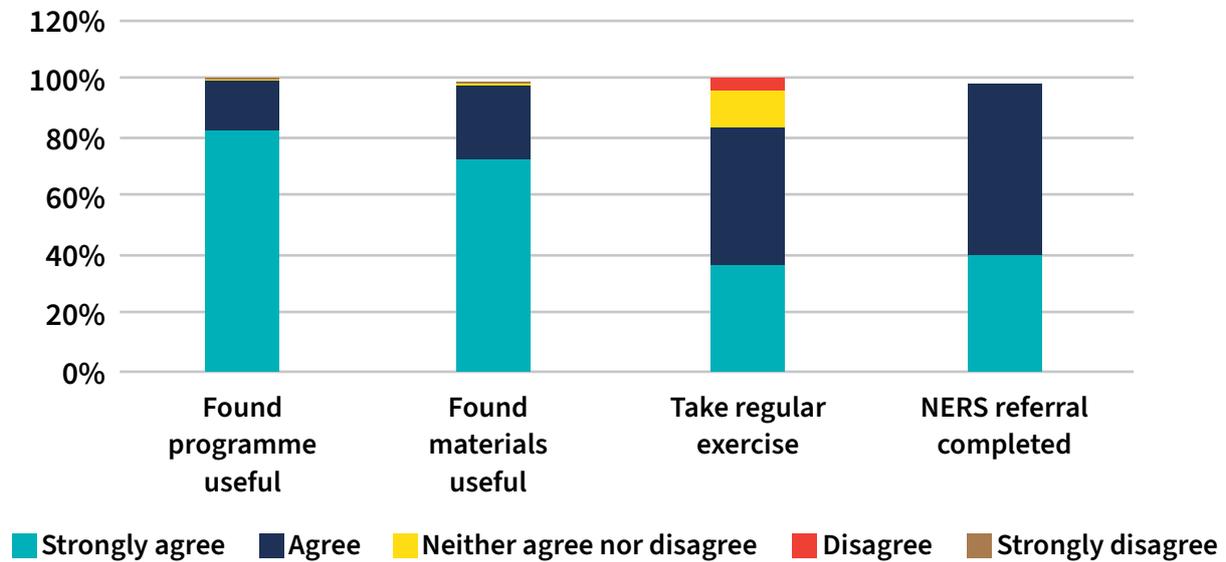


📌 **Figure 3: Social activities response percentage and after 6 weeks (v2).**

* significant difference $p < 0.05$

Usefulness of the programme

After the programme, 99% of participants agreed or strongly agreed that the programme was useful, 98% of participants agreed or strongly agreed that they found the materials useful, 83% of participants agreed or strongly agreed that they took regular exercise and 41% referral to the National Exercise Referral Scheme (NERS) were made (Figure 4).



📌 **Figure 4: Usefulness of HYHY post programme.**

Relationship between baseline CAT and changes at 6 weeks

Baseline CAT did not relate to change in 6MWT ($r=0.02, p>0.05$) or change in breathlessness at rest (Borg) $r=0.003, p=0.964$ or knowledge of condition (BKQ) ($r=0.07, p>0.05$).

Discussion

This is the first evaluation of the BLF *Helping you help yourself* community exercise and education programme for people with mild breathlessness ($MRC \leq 2$) in Wales. The study showed that there was an improvement in exercise capacity, knowledge of condition and self-management behaviours after 6 weeks of HYHY and participants found the programme useful. Additionally, baseline measures of impact of COPD did not relate to changes in 6MWT, breathlessness and knowledge of condition 6 months after the programme.

Baseline data

The demographics of the participants with complete data including gender (49% male) and age (82% over 65 years) were representative of data from the national COPD audit which included patients with COPD who were assessed for, or began, PR between 3 January and 31 March 2017 in England and Wales. The audit sample comprised 53% males and the majority of patients were aged >65 years (72%). In the present study at baseline 15% were current smokers while 22% were current smokers in the audit (Steiner et al. 2018) with 16% of patients having MRC grade 1–2 breathlessness (Steiner et al. 2017). Thus, there are some similarities in the participants of HYHY with individuals in the audit. The low percentage of patients with mild breathlessness in the audit is likely to be attributed to the delivery of pulmonary rehabilitation patients with $MRC \geq 3$ whereas HYHY specifically targeted people with MRC 2. The less severe breathlessness in the present study may explain a higher completion rate of HYHY which was 81% compared to 62% in the audit. This may be attributed to less severe disease as the participants reported infrequent GP attendances and hospital appointments, or the community programme may have been more local and convenient

(Steiner et al. 2018). Attendance at PR has previously been shown to be independently influenced by smoking status, the degree of breathlessness, frequency of hospital admissions, length of the programme and journey time (Sabit et al. 2008). The participants had a median CAT score of 18 which suggests chronic respiratory disease as it has been shown that the mean score for healthy individuals is 7 and a CAT score of 13 aligns to a grade 1 COPD GOLD classification, even though COPD was not confirmed with spirometry (Jones et al. 2013).

Change with HYHY

After 6 weeks of HYHY, 6MWT and BKQ increased; these findings are similar to those of the systematic review by Jácome & Marques (2014) that showed that exercise and QoL improved in people with mild COPD. 6-minute walk distance was increased by at least 50m in 48% ($n = 100$) of participants with 92 people exceeding the higher minimum clinically important difference (MCID) for the 6MWT which varies in the literature from 25–54m (Holland & Nici 2013) this demonstrates a clinically relevant change with HYHY. However, some of this may be attributed to a learning effect, in the absence of a practice test. This suggests that the low resource exercise and education intervention was able to improve exercise capacity. It is not known if participants' level of physical activity and/or exercise changed outside of the HYHY programme and therefore whether the education element indirectly influenced exercise capacity, or the change was solely due to the exercise component of the intervention.

Our results in people with mild breathlessness can be compared to Lewis et al. (2019) in patients with COPD confirmed by spirometry which included weekly exercise for 4 weeks, led by a senior physiotherapist and rehabilitation assistant. Improvement in knowledge of condition in the present study, by 3 points (25%), was similar to the 21% improvement in the full version of BCKQ. Although, to our knowledge no MCID for the BCKQ has been published, this improvement suggests that HYHY has a positive effect on knowledge of condition, despite the lower frequency of education and exercise training compared to traditional PR (2–3 times per week). These findings may be particularly valuable in people with milder disease as it has been suggested that community rehabilitation may facilitate ease and convenience of participation, and link to a lifestyle change rather than being applied in a hospital setting (Crisafulli & Clini 2010).

A review of studies including self-management behaviours showed improved QoL, dyspnoea and reduced all-cause mortality. These studies included the self-management behaviours of self-recognition and self-treatment of exacerbations, taking medication and eating a healthy diet, coping with breathlessness, quitting smoking and taking regular exercise (Zwerink et al. 2014). The significant improvements in self-management after 6 weeks may be attributed to the HYHY education programme which largely aligned with NICE guidance (Steiner et al. 2018). The HYHY education programme included information regarding COPD as a condition, goal setting, managing breathlessness and anxiety, being active and getting

referred to the NERS, advice on eating well, managing flare ups and medications, but did not include smoking cessation, oximetry or inhaler training. Despite the lack of specific advice on smoking cessation, there was a significant improvement in the responses to the statement 'I don't smoke', which could indicate that an education programme alone may promote people to make healthy lifestyle choices. Although there was no significant change in responses to the comment 'I understand the importance of being active/taking exercise', there was a significant increase in exercise capacity as measured by 6MWT in the participants. This may therefore indicate that the change in exercise capacity was in fact due to the exercise component rather than changes to lifestyle beyond the HYHY programme. The findings from this study indicate that behaviours such as attending groups and activities and having social contacts did change significantly after attending the programme, even though knowledge of the condition remained unchanged. Further qualitative research exploring participants experiences of taking part in community rehabilitation may help in understanding the mechanisms of behaviour change as well as design of future community programmes.

The findings from this study are similar to a randomised controlled trial in people with mild breathlessness (MRC 1 or 2) (Jolly et al. 2018) that demonstrated improvements in self-management as a consequence of a telephone coaching intervention. The theoretical basis of the intervention was social cognitive theory, whereas HYHY was underpinned by a motivational interview approach. Both approaches aim to enhance self-efficacy through goal setting (Hettema et al. 2005; Beauchamp et al. 2019) which was evidenced by a significant change in physical activity and seeking support from healthcare professionals by Jolly et al. (2018) and by agreement with statements related to social participation in the current study. Comparable results were found in an evaluation of PR for people with asthma and COPD, with significant improvements found in patient activation, health-directed behaviour and self-monitoring (Janssen et al. 2019).

At baseline, the impact of disease score as measured by CAT was median 18 (moderate impact); CAT was not measured at the end of the HYHY so it is not known if there was a change post HYHY and its inclusion would be recommended for future evaluations. Lewis et al. (2019) included participants with similar baseline CAT values which did not change after a 4-week programme. However, a previous study showed a 2.9 change immediately post PR (Sabit et al. 2008). The contrast in findings may be due to the short PR intervention, 4 weeks, by Lewis et al. (2019) compared 8 weeks by Dodd et al. (2012) a minimum of 6 weeks is recommended by the British Thoracic Society (Bolton et al. 2018).

The current study demonstrated that baseline CAT was not related to changes in 6MWT, breathlessness at rest (Borg) and knowledge of condition at the end of the HYHY programme. Dodd et al. (2012) showed that change in CAT was significantly correlated with a change in 6MWT ($r = 0.31, p = 0.01$). It is difficult to compare the findings as the current study used baseline CAT and Dodd et al. (2012) used change in CAT as the independent variable.

The implications from the current study are that improvements in exercise capacity are possible irrespective of the disease burden for people with mild breathlessness COPD.

The HYHY programme was well received with participants agreeing that the programme (99%) and materials (98%) were useful. This suggests that this low resource community programme may be a useful support mechanism to promote self-management in people with COPD and mild breathlessness.

Limitations

We acknowledge a number of limitations to our study. As HYHY was set up as a support service, we did not recruit a control group for comparison, nor was the evaluation powered to detect change in variables. Participants had self-reported COPD (not confirmed with spirometry) which may affect the validity of the CAT score. There were some missing data, and unvalidated questionnaires included in the evaluation and more consistent completion of outcome measures would have been useful. The 6MWT was completed using a 10m track which increases the number of turns and may therefore affect distance gained. It was undertaken without a practice test which means the changes may be attributed to a learning effect and given the mild breathlessness there was potential for a ceiling effect and an alternative may have been an externally-paced test. Data were collected by the exercise instructor which may have resulted in response bias. However, this reflects the limitations of a charity-funded service evaluation. We also recognise that there may be differences in people who volunteered to participate and reasons for non-completion were not explored. The study also did not explore pre-post programme health-care resource use, lung function and long-term effects of HYHY.

Conclusion

This study suggests that HYHY, a community-based rehabilitation programme, may provide benefits for people with mild breathlessness and COPD in terms of exercise capacity, knowledge of disease and self-management. The improvements in exercise capacity and knowledge of condition were independent of the impact of COPD, therefore, it is suitable for all people affected by COPD. Further research is needed to explore the experiences of people with mild COPD who have taken part in community rehabilitation programmes to further understand the mechanisms of behaviour change.

Conflict of interest

Although set up by the BLF authors, the analysis was undertaken by Cardiff University independently of the BLF who were blinded to the study analysis.

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References (check in-body text above references match the below, like 1st 'Name et al')

- Beauchamp, M. R., Crawford, K. L., & Jackson, B. (2019). Social cognitive theory and physical activity: Mechanisms of behavior change, critique, and legacy. *Psychology of Sport and Exercise, 42*, 110–117. <https://doi.org/10.1016/j.psychsport.2018.11.009>.
- Bolton, C. E., Bevan-Smith, E. F., Blakey, J. D., Crowe, P., Elkin, S. L., Garrod, R., Greening, N. J., Heslop, K., Hull, J. H., Man, W. D., Morgan, M. D., Proud, D., Roberts, C. M., Sewell, L., Singh, S. J., Walker, P. P., Walmsley, S., British Thoracic Society Pulmonary Rehabilitation Guideline Development Group, & British Thoracic Society Standards of Care Committee (2013). British Thoracic Society guideline on pulmonary rehabilitation in adults. *Thorax, 68* (suppl 2), ii1–ii30. <https://doi.org/10.1136/thoraxjnl-2013-203808>.
- Cecins, N., Landers, H., & Jenkins, S. (2017). Community-based pulmonary rehabilitation in a non-healthcare facility is feasible and effective. *Chronic Respiratory Disease, 14*(1), 3–10. <https://doi.org/10.1177/1479972316654287>.
- Crisafulli, E., & Clini, E.M. (2010). Measures of dyspnea in pulmonary rehabilitation. *Multidisciplinary Respiratory Medicine, 5*(3), 202–210. <https://doi.org/10.1186/2049-6958-5-3-202>.
- Dodd, J. W., Hogg, L., Nolan, J., Jefford, H., Grant, A., Lord, V. M., Falzon, C., Garrod, R., Lee, C., Polkey, M. I., Jones, P. W., Man, W. D., & Hopkinson, N. S. (2011). The COPD assessment test (CAT): response to pulmonary rehabilitation. A multicentre, prospective study. *Thorax, 66*(5), 425–429. <https://doi.org/10.1136/thx.2010.156372>.
- Dodd, J. W., Marns, P. L., Clark, A. L., Ingram, K. A., Fowler, R. P., Canavan, J. L., Patel, M. S., Kon, S. S., Hopkinson, N. S., Polkey, M. I., Jones, P. W., & Man, W. D. (2012). The COPD Assessment Test (CAT): short- and medium-term response to pulmonary rehabilitation. *COPD, 9*(4), 390–394. <https://doi.org/10.3109/15412555.2012.671869>.
- Golmohammadi, K., Jacobs, P., & Sin, D. D. (2004). Economic evaluation of a community-based pulmonary rehabilitation program for chronic obstructive pulmonary disease. *Lung, 182*(3), 187–196. <https://doi.org/10.1007/s00408-004-3110-2>.
- Hettema, J., Steele, J., & Miller, W. R. (2005). Motivational interviewing. *Annual Review of Clinical Psychology, 1*, 91–111. <https://doi.org/10.1146/annurev.clinpsy.1.102803.143833>.
- Holland, A. E., & Nici, L. (2013). The return of the minimum clinically important difference for 6-minute walk distance in chronic obstructive pulmonary disease. *American Journal of Respiratory and Critical Care Medicine, 187*(4), 335–336. <https://doi.org/10.1164/rccm.201212-2191ED>.
- Hogg, L., Grant, A., Garrod, R., & Fiddler, H. (2012). People with COPD perceive ongoing, structured and socially supportive exercise opportunities to be important for maintaining an active lifestyle following pulmonary rehabilitation: A qualitative study. *Journal of*

Physiotherapy, 58(3), 189–195. [https://doi.org/10.1016/S1836-9553\(12\)70110-8](https://doi.org/10.1016/S1836-9553(12)70110-8).

Lewis, A., Dullaghan, D., Townes, H., Green, A., Potts, J., & Quint, J. K. (2019). An observational cohort study of exercise and education for people with chronic obstructive pulmonary disease not meeting criteria for formal pulmonary rehabilitation programmes. *Chronic Respiratory Disease*, 16, 1479973119838283. <https://doi.org/10.1177/1479973119838283>.

Jácome, C., & Marques, A. (2014). Pulmonary rehabilitation for mild COPD: A systematic review. *Respiratory Care*, 59(4), 588–594. <https://doi.org/10.4187/respcare.02742>.

Janssen, S., Vlieland, Thea., Volker, G., & Abbink, J. (2019). Does self-management ability improve after pulmonary rehabilitation for chronic obstructive pulmonary disease? *European Respiratory Journal*, 54(suppl 63). https://erj.ersjournals.com/content/54/suppl_63/PA643.

Jones, P. W., Adamek, L., Nadeau, G., & Banik, N. (2013). Comparisons of health status scores with MRC grades in COPD: implications for the GOLD 2011 classification. *The European Respiratory Journal*, 42(3), 647–654. <https://doi.org/10.1183/09031936.00125612>.

Jolly, K., Sidhu, M. S., Hewitt, C. A., Coventry, P. A., Daley, A., Jordan, R., Heneghan, C., Singh, S., Ives, N., Adab, P., Jowett, S., Varghese, J., Nunan, D., Ahmed, K., Dowson, L., & Fitzmaurice, D. (2018). Self management of patients with mild COPD in primary care: randomised controlled trial. *BMJ (Clinical research ed.)*, 361, k2241. <https://doi.org/10.1136/bmj.k2241>.

Jones, P. W., Harding, G., Berry, P., Wiklund, I., Chen, W. H., & Kline Leidy, N. (2009). Development and first validation of the COPD Assessment Test. *The European Respiratory Journal*, 34(3), 648–654. <https://doi.org/10.1183/09031936.00102509>.

Jones, P., Miravitlles, M., van der Molen, T., & Kulich, K. (2012). Beyond FEV₁ in COPD: A review of patient-reported outcomes and their measurement. *International Journal of Chronic Obstructive Pulmonary Disease*, 7, 697–709. <https://doi.org/10.2147/COPD.S32675>.

Rollnick, S., & Miller, W.R. (1995). What is motivational interviewing? *Behavioural and Cognitive Psychotherapy*, 23(4), 325–334. <https://www.cambridge.org/core/journals/behavioural-and-cognitive-psychotherapy/article/abs/what-is-motivational-interviewing/F7E8B9E777291290E6DF0FDE37999C8D>.

Steiner, M., McMillan, V., Lowe, D., Holzhauer-Barrie, J., Mortier, K., Riordan, J., Roberts, C.M. (2018, April). *National Chronic Obstructive Pulmonary Disease (COPD) Audit Programme. Pulmonary rehabilitation: An exercise in improvement. Clinical and organisational audits of pulmonary rehabilitation services in England and Wales 2017*. Royal College of Physicians (RCP). <https://www.rcplondon.ac.uk/projects/outputs/pulmonary-rehabilitation-exercise-improvement-combined-clinical-and-organisational>.

Steiner, M. C., Lowe, D., Beckford, K., Blakey, J., Bolton, C. E., Elkin, S., Man, W. D., Roberts, C. M., Sewell, L., Walker, P., & Singh, S. J. (2017). Socioeconomic deprivation and the outcome of pulmonary rehabilitation in England and Wales. *Thorax*, 72(6), 530–537. <https://doi.org/10.1136/thoraxjnl-2016-209376>.

Sabit, R., Griffiths, T. L., Watkins, A. J., Evans, W., Bolton, C. E., Shale, D. J., & Lewis, K. E. (2008). Predictors of poor attendance at an outpatient pulmonary rehabilitation programme. *Respiratory Medicine*, 102(6), 819–824. <https://doi.org/10.1016/j.rmed.2008.01.019>.

Singh, S. J., Puhan, M. A., Andrianopoulos, V., Hernandez, N. A., Mitchell, K. E., Hill, C. J., Lee, A. L., Camillo, C. A., Troosters, T., Spruit, M. A., Carlin, B. W., Wanger, J., Pepin, V., Saey, D., Pitta, F., Kaminsky, D. A., McCormack, M. C., MacIntyre, N., Culver, B. H., Sciruba, F. C., Holland, A. E. (2014). An official systematic review of the European Respiratory Society/American Thoracic Society: measurement properties of field walking tests in chronic respiratory disease. *The European Respiratory Journal*, 44(6), 1447–1478. <https://doi.org/10.1183/09031936.00150414>.

Vogiatzis, I., Rochester, C. L., Spruit, M. A., Troosters, T., Clini, E. M., & American Thoracic Society/European Respiratory Society Task Force on Policy in Pulmonary Rehabilitation (2016). Increasing implementation and delivery of pulmonary rehabilitation: key messages from the new ATS/ERS policy statement. *The European Respiratory Journal*, 47(5), 1336–1341. <https://doi.org/10.1183/13993003.02151-2015>.

White, R., Walker, P., Roberts, S., Kalisky, S., & White, P. (2006). Bristol COPD Knowledge Questionnaire (BCKQ): testing what we teach patients about COPD. *Chronic Respiratory Disease*, 3(3), 123–131. <https://doi.org/10.1191/1479972306cd117oa>.

Zwerink, M., Brusse-Keizer, M., van der Valk, P., Zielhuis, G.A., Monninkhof, E.M., van der Palen, J., Frith, P.A., Effing, T. (2014). Self management for patients with chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews* 2014, 3. <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD002990.pub3/full>.

Appendix 1

Q1. How much do you agree or disagree with the following statements? Please tick (✓) 1 box for each statement

With regards to your lung condition...	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I have a good understanding of my lung condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to find further information about managing my lung condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do if I have a flare-up (exacerbation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't smoke	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
I eat healthily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand the importance of being active/taking exercise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am happy with my social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a network of friends and social contacts whom I can go to for support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I attend groups and activities that are of interest to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>