Pulmonary Rehabilitation Improves Self-Management Ability in Subjects With Obstructive Lung Disease

Steffi MJ Janssen, Thea PM Vliet Vlieland, Gerard Volker, Martijn A Spruit, and Jannie J Abbink

BACKGROUND: Optimizing self-management is a key element in multidisciplinary pulmonary rehabilitation in patients with asthma or COPD. This observational study aimed to investigate the changes in self-management following pulmonary rehabilitation in subjects with chronic lung disease. METHODS: Data were prospectively and routinely gathered at initial assessment and discharge in subjects taking part in a 12-week multidisciplinary out-patient pulmonary rehabilitation program. Measures of self-management included the Patient Activation Measure (PAM), the Health Education Impact Questionnaire (HEIQ) (8 subscales), a Self-Efficacy Questionnaire (2 subscales), the Lung Information Needs Questionnaire (LINQ), and the Health Literacy Questionnaire (HLQ) (9 subscales). Mean differences with 95% CI and effect sizes were computed. RESULTS: A total of 70 subjects (62.9% women) were included, with a median age of 63.5 y; most of the subjects had been diagnosed with COPD (77%). Between admission and discharge, all measures of self-management increased significantly except for the HEIQ subscales of constructive attitudes and approaches, social integration and support, and health services navigation; and the HLQ subscale of social support for health. The largest improvements (effect size > 0.55) were seen for the PAM (0.57); the HEIQ subscales of health-directed behavior (0.71), self-monitoring and insight (0.62), and skill and technique acquisition (1.00); the HLQ subscales of having sufficient information to manage my health (1.21) and actively managing my health (0.66); and the LINQ (1.85). CONLCUSIONS: Self-management, including activation, improved significantly in subjects with asthma or COPD who took part in a multidisciplinary pulmonary rehabilitation program. *Key words: self-management; patient activation; COPD; asthma; pulmonary rehabilitation.* [Respir Care 2021;66(8):1271–1281. © 2021 Daedalus Enterprises]

Introduction

For symptomatic patients with moderate to severe obstructive lung diseases like COPD or asthma, pulmonary rehabilitation (PR) is recommended to be a part of routine care.[1] Optimizing a patient's self-management, defined as "an individual's ability to detect and manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition,"[2] is a key element of PR.[1] Effective self-management includes, among other things, having a personalized action plan and knowing how to use it, being able to ask questions of health care providers, setting goals, and making decisions.[3]

Regarding the effectiveness of PR programs in subjects with obstructive lung diseases, significant and clinically relevant improvements in dyspnea, fatigue, emotional function,

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sense of control over the condition, and exercise capacity were found in a systematic literature review including 65 randomized controlled trials.[4] The extent to which self-management skills improve cannot be concluded from this Cochrane systematic review, as none of the included studies used outcomes regarding self-management. This is striking, as there are various measures available for the different aspects of self-management, whether specifically for patients with asthma or COPD or not, such as the Health Education Impact Questionnaire (HEIQ), the Self-Efficacy questionnaire, or the Lung Information Needs Questionnaire (LINQ).[5-8] A previous evaluation study, which used the PRAISE tool, did report a significant improvement in self-efficacy after PR.[9]

A relatively new concept in this respect is patient activation, or the readiness to self-manage. This concept of patient activation can be measured using the Patient Activation Measure (PAM)-13 questionnaire, which distinguishes 4 levels of activation. A higher level implies more activation to engage in self-management behavior.[10-13] Previous literature indicates that subjects with asthma or COPD referred from primary to secondary care in The Netherlands show lower levels of activation; approximately 57% show little to no activation (PAM level 1 or 2).[14] This is in agreement with the observation that about 40% of patients with COPD are able to perform adequate self-management behavior with regard to following a written action plan to prevent hospital re-admissions.[15,16] Specific self-management interventions were shown to have an impact on the level of activation as measured with the PAM in subjects with COPD and have demonstrated that this concept can change over time; in both a longitudinal study ($N = 105$) and a retrospective study ($N = 38$) in subjects with COPD, a statistically significant increase in PAM score was noted 6 months after 6–7 weeks of self-management intervention.[17,18] Subjects with improved PAM scores exhibited better quality of life, less psychological distress, and an improvement in their self-management abilities.[17,19] Recently, McNamara et al[20] reported a significant improvement in patient activation following an 8-week, hospital-based, out-patient exercise training program, combined with weekly structured education sessions in subjects with different types of chronic lung disease. To date, the impact of a true multidisciplinary PR program on various aspects of self-management, including patient activation, in subjects with asthma or COPD is a relatively under-researched area.

Therefore, the aim of this study was to investigate changes of various measures of self-management, including the level of patient activation, after a 12-week multidisciplinary PR program in subjects with asthma or COPD.

QUICK LOOK

Current knowledge

Optimizing self-management is a key element in multidisciplinary pulmonary rehabilitation in patients with asthma or COPD. To date, the impact of a true multidisciplinary pulmonary rehabilitation program on various aspects of self-management, including patient activation, in subjects with asthma or COPD is a relatively under-researched area.

What this paper contributes to our knowledge

This study emphasized the outcome patient activation, combined with other measures of self-management, and positive changes were found over time. Self-management is a key element of pulmonary rehabilitation, and in subjects with asthma and COPD, significantly improved after participation in a multidisciplinary pulmonary rehabilitation program.

Methods

Study Design

This longitudinal study used an observational design involving analyses of data that were prospectively and routinely gathered as part of a PR program in a specialized regional rehabilitation center, the Basalt Rehabilitation Center in Leiden, The Netherlands. According to the National Central Committee on Research Involving Human Subjects, this type of study does not require approval from an ethics committee,[21] and no informed consent was necessary because the data used in this study were collected as a part of usual care. The local Research Review Board of Basalt approved this study. This study was conducted in accordance with the guidelines for good research practice and guidelines of the Declaration of Helsinki.[22]

Subjects

The analysis was performed in consecutive subjects who were referred to this out-patient PR program between March 2016 and July 2017, except for those who could not complete questionnaires due to insufficient reading or writing skills in Dutch ($n = 3$).

Intervention

The 12-week rehabilitation program was based on the official American Thoracic Society and European Respiratory Society Statement on Pulmonary Rehabilitation.[1] The

program consisted of supervised exercise sessions (60–90 min) 3 times a week, and weekly consultations with members of the multidisciplinary team. Both individual consultations and group sessions were planned regarding at least exacerbation management, including a written and personalized action plan, medication adherence, energy conservation, smoking cessation when applicable, and physical activity. More detailed information is given in the appendix (see the supplementary materials at http://www.rcjournal.com). The psychological basis of the program lies in the so called stress-coping model.[23] To improve subjects' self-management skills, motivational interviewing techniques were used by the different disciplines.[24]

Assessments

Except for sociodemographic characteristics, all assessments were performed at the initial assessment and at discharge. Sociodemographic characteristics included sex, age, relational status, smoking status, the number of pack-years, and educational level. The number of comorbidities, exacerbations, and lung-related hospital admissions were checked by the pulmonologist during the first consultation.

Measures of self-management included several questionnaires. The subjects' level of patient activation was measured with the Patient Activation Measure (PAM-13), a 13-item questionnaire that requires response on a 5-point Likert scale. The total score is calculated using the scoring spreadsheet provided by Insignia Health, which then can be transformed into a level score. Scores range from 0 to 100, which lead to a level score of 1–4.[12] Level 1 corresponds to the lowest level of activation (eg, patients are passive and lack confidence, their perspective is "My doctor is in charge of my health"), whereas level 4 is the highest level patients can reach (eg, they have adopted new behaviors but may struggle in times of stress or change).[12,13,25] An improvement of ≥ 4 points on the PAM total score is considered a meaningful change.[17]

Each subject's ability to deal with the disease (ie, self-management) on a daily basis was measured using the Health Education Impact Questionnaire (HEIQ).[5] The questionnaire consists of 40 questions that can be answered using a 4-point rating scale, resulting in scores in 8 different domains; no sum score can be computed. Higher scores imply better self-management abilities.

Using the Health Literacy Questionnaire (HLQ), each subject's ability to navigate the health care system and to learn skills to manage health was measured. The questionnaire consists of 9 domains, and higher scores imply better skills regarding the specific domain.[26]

To determine subjects' information needs, the Dutch translation of the Lung Information Needs Questionnaire (LINQ) was used.[6] Higher scores imply more information needs. An informal assessment of the minimal clinically important difference suggests a change of minus one point to be relevant for patients with COPD.[6]

To measure subjects' self-efficacy, the self-efficacy questionnaire by Sullivan was used.[7] The questionnaire consists of 13 items, and 2 separate total scores can be calculated, one for controlling symptoms and one for maintaining function. Lower scores imply more confidence and self-efficacy.

Physical and emotional measures included a cardiopulmonary exercise test, the modified Medical Research Council score, and the Hospital Anxiety and Depression Scale. The cardiopulmonary exercise test was performed following the ERS/ATS recommendations.[27] Outcome measures were maximum load (watts and percent of predicted) and maximum oxygen uptake. When subjects had severe to very severe COPD (GOLD III/IV), a submaximal constant work rate test was performed at 75% of peak work rate achieved in the cardiopulmonary exercise test, with cycle time as the main outcome.

Using the modified Medical Research Council score, the amount of dyspnea as experienced by subjects was measured. The modified Medical Research Council score is a 5-point rating score.[28] A higher score implies more dyspnea. Disease-specific health-related quality of life was measured using the Chronic Respiratory Disease Questionnaire (CRQ).[29] The CRQ has 20 questions, which can be summarized into 4 domains. Higher scores imply a better quality of life. A 10-point difference on the total score is the minimal clinically important difference in patients with COPD.[30]

The Hospital Anxiety and Depression Scale (HADS) consists of two 7-item scales, one for anxiety and one for depression.[31] The questionnaire is used as a screening tool, with higher scores indicating more complaints. When a patient scores 11–21 points, there is probable depression or anxiety.[32] The minimal clinically important difference in patients with COPD was estimated to be ~ 1.5 points.[33]

Statistical Analysis

The SPSS Statistics 22 package was used (IBM, Armonk, New York), employing descriptive and inferential statistics to present the data. Statistical comparisons of initial assessment and discharge data were done using the paired *t* test, Wilcoxon matched pairs signed rank sum *t* test, or the Fisher exact test, where appropriate. Mean differences with 95% CI were computed. Additionally, the *d*-type effect size was calculated, where 0.2 represents a small effect, 0.5 a medium, and 0.8 a large effect.[34]

Results

Baseline Characteristics

Between March 2016 and July 2017, 108 patients diagnosed with asthma and/or COPD were referred to PR. As

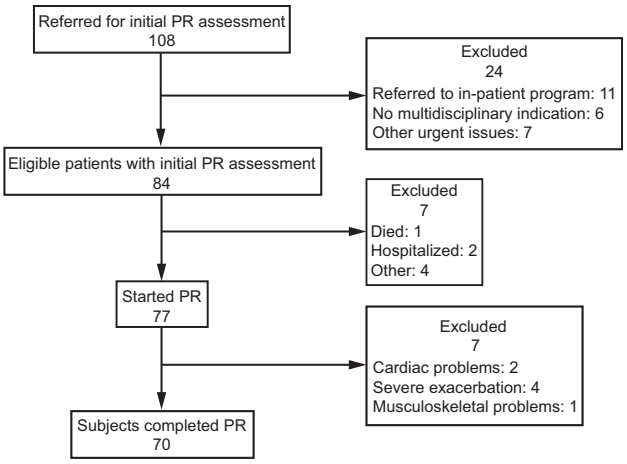

Fig. 1. Flow chart. PR = pulmonary rehabilitation.

shown in Figure 1, 24 patients did not meet the inclusion criteria for the out-patient PR; of the 84 patients who completed the initial assessment, 77 started the PR program. Seven patients dropped out during the program, resulting in a total of 70 patients who completed the program. Table 1 displays the characteristics of these groups.

The median age of the subjects who completed the program was 63.5 y (range 29–84 y), and 26 (37.2%) were male. The majority of the subjects had COPD (54 subjects, 77.1%) and had 1–2 comorbidities (39 subjects, 55.7%). Regarding PAM levels, 62.1% of the subjects scored PAM level 1 or 2. When looking at differences at baseline between subjects with COPD or asthma (Table 2), subjects differed significantly in smoking status, pack-years, level of education, lung function, body mass index, exercise capacity measured with cardiopulmonary exercise test and modified Medical Research Council score. No significant differences were found in baseline measures of the PAM, LINQ, or CRQ.

Changes Following PR

Table 3 shows the changes over time regarding the self-management outcome measures. With reference to the PAM, statistically significant changes were seen in both PAM score (6.88 [4.04–9.71] points) as well as in PAM level (0.54 [0.32–0.76]). In total, 35 (59.3%) of the subjects exceeded the minimal detectable change of 4 points. Figure 2 shows the changes in PAM levels. The majority of the subjects improved in PAM level, with 24 (41%) subjects improving by 1 level and 7 (12%) subjects displaying an increase of 2 levels.

All outcome measures for self-management showed statistically significant improvements over time except for HLQ 4 and HEIQ 5, 7, and 8. Effect sizes were medium for the PAM (0.57), the HEIQ 1 (0.71), the HEIQ 4 (0.62), the HLQ 3 (0.66), the HLQ 6 (0.50), and the HLQ 7 (0.50). Effect sizes were large for the HEIQ 6 (1.00), the HLQ 2 (1.21), and the total LINQ score (1.85).

Table 4 shows the outcomes for measures of physical and emotional status, where for all outcomes except for the maximum oxygen uptake, subjects showed a statistically significant improvement ($P \leq .01$). Effect sizes were the largest for endurance exercise capacity (0.61) and the CRQ total score (0.99).

Responders versus Non-Responders

Subjects with an increase in PAM level (level change +1 or +2) were designated as responders ($n = 31$, 55%), whereas subjects with no change or a decrease (level change 0 or –1) were classified as nonresponders ($n = 25$, 45%). All subjects with a PAM level 4 score at initial assessment ($n = 3$) also scored a PAM 4 at discharge; these subjects were excluded from the analysis due to the ceiling effect (ie, they had no room to improve). Of the 25 nonresponders, 14 subjects (56%) scored an initial PAM level 3, with the remaining subjects scoring level 1 or 2 ($n = 6$ [24%] and $n = 5$ [20%], respectively). For the responders, the number of subjects scoring level 3 at initial assessment was only 16% ($n = 5$), with 14 (45%) and 12 (39%) scoring level 1 or level 2, respectively. Table 5 presents the mean differences in outcomes between the responders and the nonresponders at discharge. The mean change in PAM score, LINQ score, and various domains of the HEIQ and HLQ differed significantly ($P \leq .05$). Responders show a significantly greater decline in information needs than the nonresponders (mean difference –3.18 [–5.05 to –1.31], $P < .001$). In the domains HEIQ 4, HEIQ 6, HEIQ 8, HLQ 1, HLQ 2, HLQ 4, and HLQ 6 responders show greater improvements. The responders improved significantly on all outcomes, except for endurance exercise capacity, whereas in the nonresponders significant improvements were seen for 9 of 27 outcomes.

Discussion

This observational study found that, besides the known improvements in exercise performance and quality of life, self-management, including patient activation, improved significantly after a 12-week PR program in subjects with asthma or COPD. Although enhancing self-management is an important aim of PR, so far literature demonstrating the impact of PR programs on self-management is scarce. In our study, improvements were consistently demonstrated for all different measures of self-management we used. Most striking were the improvements observed for the LINQ, the HEIQ 6, the HLQ 2, and Self-Efficacy (control symptoms), with effect sizes ≥ 0.8. Subscales regarding social support (ie, HEIQ 7, HLQ 4) did not display a significant improvement.

Table 1. Characteristics of Subjects With Asthma or COPD by Completion of the Pulmonary Rehabilitation Program

	Completed the Program ($n = 70$)	Did Not Complete the Program ($n = 7$)
Sex, male	26 (37)	2 (29)
Age, y	64 (29–84)	68 (58–78)
Level of education*		
Low	43 (67)	4 (67)
High	21 (33)	2 (33)
Living arrangements, living alone	24 (34)	4 (57)
Body mass index, kg/m^2†	26 (17–49)	19 (17–26)
Diagnosis†		
Asthma	16 (23)	0 (0)
COPD	54 (77)	7 (100)
GOLD status		
I	0	0
II	13 (24)	0
III	30 (56)	5 (71)
IV	11 (20)	2 (29)
FEV_1/VC†	40 (22–82)	33 (19–41)
FEV_1, % of predicted	43 (22–116)	38 (16–53)
Smoking status		
Current smoker	14 (20)	1 (14)
Stopped smoking (< 4 weeks)	48 (69)	6 (86)
Never smoked	8 (11)	0
Pack-years, in smokers	35 (0–100)	36 (20–55)
Number of comorbidities‡		
0	13 (19)	1 (14)
1 – 2	39 (56)	2 (29)
>2	18 (26)	4 (57)
Number of exacerbations in the past 12 months		
0	14 (20)	1 (14)
1–2	28 (41)	3 (43)
> 2	27 (39)	3 (43)
Number of lung-related hospital admissions in the past 12 months		
0	45 (71)	5 (71)
1–2	14 (22)	0
> 2	4 (6)	2 (29)

Data are reported as median (range) or *n* (%).

* Low = primary/lower vocational education/secondary education/intermediate vocational education; High = higher vocational education/university.

† $P \leq .05$.

‡ Diabetes, hypertension, myocardial infarction, heart failure, arrhythmia, cerebrovascular accident, lung cancer, osteoporosis, obesity, underweight, anxiety, depression, coronary artery disease, or peripheral vascular disease.

This could be due to the fact that the program more strongly emphasizes the patient's knowledge, behavior, and physical capacity than it addresses the patient's caregivers and social environment.

Bringsvor et al[35] conducted a randomized controlled trial to evaluate the effects of a self-management intervention known as "Better Living With COPD," which consisted of weekly 2-h group conversations over 11 weeks compared with usual care. Different outcome measures were used, including the HEIQ, which displayed a significant but smaller improvement compared to our study. The largest improvements were seen in HEIQ 4, HEIQ 5, and HEIQ 6, with 0.38 as the largest effect size. Our findings display effect sizes in 5 of 8 HEIQ domains with an effect size up to 1.0. A reason for these differences could be the fact that Bringsvor et al[35] did not include exercise in their intervention, which seems to be related to HEIQ 1, in which we saw a significant improvement (effect size 0.71).

The LINQ has been investigated in a few other studies as well. Jones et al[8] and Nolan et al[36] reported that the LINQ improves with PR, although we noted a greater improvement with an effect size of 1.85 compared to 0.74. This may be due to the fact that the program that was offered in the study by Nolan et al[36] was limited to an out-patient

Table 2. Subject Characteristics at Baseline

	COPD ($n = 54$)	Asthma ($n = 16$)	P
Male	22 (41)	4 (25)	.25
Age, y	66 ± 9	54 ± 14	< .001
Living arrangements, living alone	19 (35)	5 (31)	.77
Exacerbations in the past 12 months			.97
0	10 (19)	4 (25)	
1–2	22 (42)	6 (38)	
> 2	21 (40)	6 (38)	
Lung-related hospital admissions in the past 12 months			.77
0	33 (69)	12 (80)	
1–2	11 (23)	3 (20)	
> 2	4 (8)	0 (0)	
Smoking status			< .001
Never smoked	0 (0)	8 (50)	
Current smoker	14 (26)	0 (0)	
Stopped smoking (< 4 weeks)	40 (74)	8 (50)	
Pack-years in smokers	40 (10–100)	0 (0–42)	< .001
Modified Medical Research Council	3 (1–5)	3 (2–4)	.02
Chronic Respiratory Disease Questionnaire	80 ± 19	76 ± 18	.46
Level of education			< .001
Low	38 (76)	5 (36)	
High	12 (24)	9 (64)	
Lung Information Needs Questionnaire	10 ± 3	9 ± 4	.62
Patient Activation Measure score	51 (32–91)	51 (41–73)	.90
Level 1	17 (33)	6 (40)	.87
Level 2	15 (30)	3 (20)	
Level 3	17 (33)	5 (33)	
Level 4	2 (4)	1 (7)	
Self-Efficacy Questionnaire			
Control symptoms	21 (9–38)	19 (10–33)	.64
Maintain function	8 (3–13)	8 (5–14)	.20
Hospital Anxiety and Depression Scale			
Anxiety	6 (0–17)	6 (0–15)	.60
Depression	6 (1–15)	5 (2–14)	.51
FEV_1	1.1 (0.5–2.4)	1.9 (0.8–3.9)	< .001
FEV_1 % of predicted	41 (22–71)	80 (27–116)	< .001
FEV_1/VC	37 (22–59)	61 (32–82)	< .001
FEV_1/C % of predicted	45 (30–77)	80 (44–96)	< .001
Body mass index, kg/m^2	25 (17–36)	31 (24–49)	< .001
FFM-I*	14 (12–17)	16	.40
Comorbidities			.81
0	10 (19)	3 (19)	
1–2	30 (56)	9 (56)	
> 2	14 (26)	4 (25)	
Peak exercise capacity, % predicted	39 (9–112)	77 (30–127)	< .001
Constant work rate test, s	587 (60–900)	639 (377–900)	.84

Data are reported as median (range), mean ± SD or n (%). $N = 70$ subjects.
* $n = 1$.

program that took place twice a week (1 h of exercise training and 1 h of education) for 8 weeks with an unsupervised exercise session at home, which seems significantly less intensive than our 12-week PR program. Baseline LINQ, modified Medical Research Council, and CRQ measures were comparable to this study. The PR program described by Jones et al[8] was also more limited, with the number of sessions ranging between 1 and 3 sessions a week, lasting

Table 3. Patient Activation, Education Impact, Health Literacy, Information Needs, Self-Efficacy and Rehabilitation Outcomes in Subjects Completing Pulmonary Rehabilitation

	Initial Assessment	Discharge	Mean Difference (95% CI)	Effect Size	Missing
Patient Activation Measure score*	51 (32–91)	56 (44–100)	7 (4–10)	0.57	11
Level 1*	23 (35)	7 (12)			
Level 2	18 (27)	19 (31)			
Level 3	22 (33)	24 (39)			
Level 4	3 (5)	11 (18)			
Health Education Impact Questionnaire					
Subscale 1: Health-directed behavior*	2.6 (1–4)	3 (1.3–4)	0.4 (0.3–0.5)	0.71	8
Subscale 2: Positive and active engagement in life*	2.7 (1.6–4.0)	3 (1.6–4)	0.2 (0.1–0.3)	0.31	8
Subscale 3: Emotional well-being*	2.8 (1.3–4)	3 (1.5–4)	0.2 (0.7–0.3)	0.34	8
Subscale 4: Self-monitoring and insight*	2.8 (1.8–4)	3 (2.5–4)	0.3 (0.1–0.4)	0.62	8
Subscale 5: Constructive attitudes and approaches*	3 (2–4)	3 (2–4)	0.1 (0.0–0.3)	0.22	8
Subscale 6: Skill and technique acquisition*	2.5 (1.8–4)	3 (1–4)	0.4 (0.3–0.5)	1.00	8
Subscale 7: Social integration and support	3 (1.2–4)	3 (1–4)	0.1 (0.0–0.2)	0.20	8
Subscale 8: Health services navigation	3 (1.8–4)	3 (2–4)	0.1 (–0.1 to 0.2)	0.21	8
Health Literacy Questionnaire					
Subscale 1: Feeling understood and supported by health care providers*	3 (1–4)	3 (1.8–4)	0.2 (0.1–0.4)	0.43	10
Subscale 2: Having sufficient information to manage my health*	2.5 (1.8–4)	3 (2.5–4)	0.5 (0.4–0.7)	1.21	10
Subscale 3: Actively managing my health*	2.6 (1.4–4)	3 (1.8–4)	0.3 (0.2–0.4)	0.66	10
Subscale 4: Social support for health	2.8 (1.2–3.6)	3 (1.2–4)	0.1 (–0.2 to 0.2)	0.14	10
Subscale 5: Appraisal of health information*	2.4 (1.2–4)	2.8 (1.6–4)	0.2 (0.1–0.4)	0.47	10
Subscale 6: Ability to actively engage with health care providers*	3.6 (1.6–5)	4 (2.4–5)	0.3 (0.1–0.4)	0.42	10
Subscale 7: Navigating the health care system*	3.3 (1.7–5)	3.7 (2.5–5)	0.3 (0.2–0.5)	0.50	10
Subscale 8: Ability to find good health information*	3.6 (1.6–5)	3.8 (2.6–5)	0.3 (0.2–0.5)	0.50	10
Subscale 9: Understand health information well enough to know what to do*	3.8 (1.8–5)	4 (3–5)	0.2 (0.1–0.4)	0.34	10
Lung Information Needs Questionnaire*	9.8 ± 3.4	4.2 ± 2.6	–5.5 (–6.5 to –4.5)	1.85	11
Self-Efficacy Questionnaire					
Control symptoms*	21 (9–38)	17 (7–26)	–4.4 (–5.9 to –2.8)	0.79	8
Maintain function*	8 (3–14)	7 (2–11)	–1.1 (–1.7 to –0.4)	0.40	8

Data are reported as median (range), mean ± SD or *n* (%). $N = 70$ subjects.
* $P \leq .05$.

∼ 2 h and consisting of exercise or education or both. The fact that both programs were significantly less extensive and less supervised than ours could be an explanation for the differences in effect size. McNamara et al[20] studied the effects of an 8-week out-patient PR program consisting of 16 one-hour sessions of supervised individualized exercise training and structured education sessions delivered in a group setting by a team of multidisciplinary health professionals in Australia. These authors reported improvements in outcomes on the PAM and LINQ, but these improvements were less extensive than what we noted in our study (PAM changes from 60.5 to 65.4, LINQ –3.0). An explanation could be that their baseline PAM values were higher and therefore had less room for improvement. Moreover, this Australian PR program consisted only of exercise training and education, while our PR program was a true multidisciplinary program, including multiple health care professionals who had group sessions and 1-to-1 sessions, tailoring the PR program to the needs of the subjects (see the supplementary materials at http://www.rcjournal.com).

Turner et al[17] conducted a longitudinal study to investigate the effects of a complementary self-management program in 131 subjects with COPD in primary and secondary care measured with the PAM. Almost 50% of the subjects with COPD achieved the meaningful change of 4 points on the PAM score. Our study showed a percentage of 59% of subjects reaching this improvement. Although their characteristics seem comparable at baseline, PAM scores at baseline were higher in the study by Turner et al.[17] In addition, our program was more extensive, was guided only by professionals, and lasted several weeks longer, possibly explaining the difference in response.

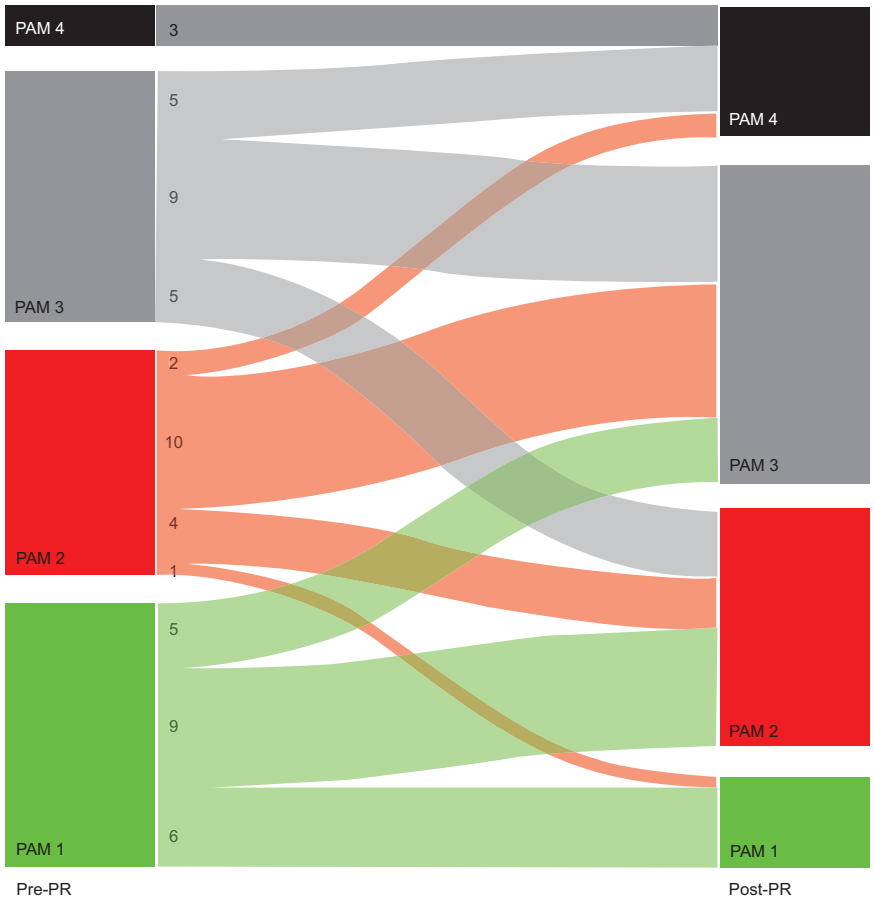

Fig. 2. Number of subjects and the shift in PAM level from initial assessment to discharge ($N = 59$). Flow lines indicate the changes in PAM level, with the number of subjects represented by the thickness of the lines. PAM = Patient Activation Measure; PR = pulmonary rehabilitation.

Table 4. Physical and Emotional Outcomes in Subjects Completing Pulmonary Rehabilitation

	Initial Assessment	Discharge	Mean Difference (95% CI)	Effect Size	Missing
Exercise tolerance					
Peak exercise capacity, watt*	58 (3–189)	88 (18–217)	8 (3–13)	0.19	30
Peak exercise capacity, % of predicted*	46 (9–127)	63 (23–143)	6 (2–10)	0.19	30
$\dot{V}_{O_2}$max, mL/min	1,195 ± 398	1,395 ± 454	41 (–36 to 119)	0.09	34
$\dot{V}_{O_2}$ max, % of predicted	73 ± 26	80 ± 26	2 (–3 to 6)	0.06	34
Constant work rate test, s*	506 (60–900)	640 (145–900)	171 (44–297)	0.61	54
Perceived dyspnea and quality of life					
Modified Medical Research Council dyspnea scale*	3 (1 - 5)	3 (1 – 5)	–1 (–1 to –0)	0.44	8
Chronic Respiratory Disease Questionnaire*	80 ± 19	98 ± 19	18 (14–22)	0.99	8
Hospital Anxiety and Depression Scale					
Anxiety*	6 (0–17)	4 (0–13)	–2 (–3 to –1)	0.39	8
Depression*	6 (1–15)	4 (0–14)	–1 (–2 to –1)	0.38	8

Data are reported as median (range), mean ± SD or *n* (%). $N = 70$ subjects.
* $P \leq .05$.
$\dot{V}_{O_2}$ = oxygen uptake

When looking at differences between responders and nonresponders, it is striking that there were no significant differences in quality of life, exercise tolerance, or dyspnea between these groups. As previously suggested, higher PAM scores would imply a better quality of life. However, because PR is a comprehensive program, there are more

Table 5. Change Scores of Various Outcome Measures in Responders and Non-Responders as Well as Differences in Change Scores.

	Responders ($n = 31$)	Nonresponders ($n = 25$)	Mean Difference (95% CI)	P
Patient Activation Measure score	12.9 (1.0–15.9) *	–1.5 (–4.4 to 1.4)	14.5 (1.3–18.6)	< .001
Health Education Impact Questionnaire				
Subscale 1: Health-directed behavior	0.4 (0.3–0.6)*	0.4 (0.2–0.6)*	0.0 (–0.2 to 0.3)	.80
Subscale 2: Positive and active engagement in life	0.2 (0.1–0.3)*	0.01 (–0.1 to 0.3)	0.1 (–0.1 to 0.3)	.30
Subscale 3: Emotional well-being	0.3 (0.2–0.5)*	0.1 (–0.1 to 0.4)	0.2 (–0.1 to 0.4)	.17
Subscale 4: Self-monitoring and insight	0.4 (0.2–0.5)*	0.1 (–0.1 to 0.3)	0.3 (0.1–0.5)	.02
Subscale 5: Constructive attitudes and approaches	0.2 (0.0–0.4)*	0.0 (–0.2 to 0.2)	0.2 (–0.1 to 0.5)	.13
Subscale 6: Skill and technique acquisition	0.5 (0.4–0.6)*	0.2 (0.1–0.3)*	0.3 (0.1–0.5)	.01
Subscale 7: Social integration and support	0.2 (0.1–0.3)*	0.1 (–0.2 to 0.2)	0.1 (–0.1 to 0.4)	.22
Subscale 8: Health services navigation	0.3 (0.1–0.4)*	–0.2 (–0.4 to 0.0)	0.4 (0.2–0.7)	< .001
Health Literacy Questionnaire (HLQ)				
Subscale 1: Feeling understood and supported by health care providers	0.3 (0.1–0.5)*	–0.0 (–0.2 to 0.1)	0.3 (0.1–0.6)	.01
Subscale 2: Having sufficient information to manage my health	0.7 (0.5–0.9)*	0.2 (0.0–0.4)*	0.5 (0.2–0.7)	< .001
Subscale 3: Actively managing my health	0.4 (0.2–0.5)*	0.2 (0.1–0.4)*	0.1 (–0.1 to 0.3)	.24
Subscale 4: Social support for health	0.12 (0.0–0.3)*	–0.1 (–0.2 to 0.1)	0.2 (0.0–0.4)	.03
Subscale 5: Appraisal of health information	0.3 (0.1–0.4)*	0.2 (–0.0 to 0.3)	0.1 (–0.1 to 0.3)	.30
Subscale 6: Ability to actively engage with health care providers	0.4 (0.2–0.6)*	0.1 (–0.3 to 0.4)	0.4 (–0.0 to 0.7)	.04
Subscale 7: Navigating the health care system	0.4 (0.3–0.6)*	0.2 (–0.1 to 0.4)	0.3 (0.0–0.6)	.09
Subscale 8: Ability to find good health information	0.3 (0.1–0.5)*	0.3 (0.0–0.6)*	0.1 (–0.3 to 0.4)	.72
Subscale 9: Understand health information well enough to know what to do	0.3 (0.1–0.5)*	0.1 (–0.2 to 0.4)	0.2 (–0.1 to 0.5)	.19
Information needs				
Lung Information Needs Questionnaire	–6.7 (–8.1 to –5.3)*	–3.5 (–4.6 to –2.4)*	–3.2 (–5.1 to –1.3)	< .001
Self-Efficacy Questionnaire				
Control symptoms	–5.8 (–7.9 to –3.8)*	–3.4 (–6.2 to –0.5)*	–2.5 (–5.8 to 0.8)	.14
Maintain function	–1.3 (–2.1 to –0.4)*	-.8 (-1.9–.3)	–0.5 (–1.8 to 0.9)	.51
Exercise tolerance				
Peak exercise capacity (% predicted)	7.0 (1.5–12.4)*	-1.1 (-6.9–4.8)	8.0 (–0.3 to 16.4)	.06
Endurance exercise capacity, s	197.3 (–96.6 to 491.1)	154.0 (3.3–304.7)*	43.3 (-25.8–337.3)	.75
Perceived dyspnea and quality of life				
Modified Medical Research Council	–0.6 (–1.0 to –0.2)*	–0.4 (–0.8 to 0.1)	–0.2 (–0.8 to 0.3)	.41
Chronic Respiratory Disease Questionnaire	21.0 (14.7–27.3)*	14.2 (7.2–21.1)*	6.8 (–2.4 to 16.1)	.14
Hospital Anxiety and Depression Scale				
Anxiety	–2.1 (–3.2 to –1.0)*	-1.5 (-3.4–.4)	–0.6 (–2.6 to 1.5)	.57
Depression	–1.9 (–2.8 to –1.0)*	-.6 (-1.6–.4)	0.7 (–2.7 to 0.1)	.06

Data are reported as mean difference (95% CI).
Subjects who scored a PAM 4 at baseline ($n = 3$) were excluded form analysis due to the ceiling effect (ie, no room to respond).
* $P \leq .05$, significant mean differences in group (initial assessment vs discharge).

factors involved that can affect the subjects' quality of life, such as psychological support.

Outcomes like exacerbation management or health care utilization were not included is this study but might be a recommendation for further research to investigate the effect of improved activation for self-management on these outcomes. When looking at the initial PAM scores in responders versus nonresponders, the nonresponders clearly have higher initial scores and therefore less room for improvement, possibly explaining the lack of increase in PAM level.

An advantage of the PAM-13 in comparison to the other measures of self-management is that it consists of only 13 items, so the burden on a patient to complete the form is minimal. Also, the PAM-13 computes a sum score presented as a score or a level, as opposed to the HEIQ and the HLQ, which compute 8 and 9 different domain scores, respectively, without a sum score, which makes them less clear and insightful for clinicians in daily practice where time is precious. Measuring a patient's level of activation can be of great value to customize the care that is provided. Patients who score low on activation might need a different approach compared to patients with a high PAM score, which is a sign of greater skill regarding self-management. This is not a standard of care yet, but we do know that one size does not fit all. Results may be satisfying overall, but on the individual level there is room for improvement,

which may be achieved by tailoring care to the skill level the patient already has.

This study has some methodological considerations. First, it had an observational design. There was no usual-care control group with which to compare this group of subjects, and the effects of the intervention cannot exclusively be assigned to the PR program. Second, data were gathered routinely in daily practice, and the self-administered questionnaires were sent to the subject's home address at the time, where they could complete the forms. Despite several checks, there were some missing data. Finally, the design of this study does not allow the determination of the active components of the multidisciplinary PR program that contributed to the improvements in self-management and patient activation. However, it seems reasonable that the fact that this concerns a comprehensive, multidisciplinary, out-patient PR program with extensive supervision in both structured exercise as well as education generates more improvement than less extensive programs.

Strengths of this study were that there were 2 moments in time where the measurements were done. To date, there is only one other study[20] that examined changes over time in subjects with asthma or COPD after a PR program combining exercise and education, but the subjects in that study had notably less severe COPD and higher levels of activation at the start of the program.

As expected from earlier studies, the level of activation at the initial assessment in this study was low.[10,16] However, with a median score of 51 for the level of activation, and 62% of the subjects in PAM level 1 or level 2, our group of subjects scored even lower than other groups described in the literature, possibly implying an even more severe burden of disease.

Conclusions

Significant improvements were seen in self-management, including the level of activation, in subjects with asthma or COPD after a 12-week out-patient PR program. Future studies are needed to better understand which PR components have contributed to this added value of PR.

REFERENCES

1. Spruit MA, Singh SJ, Garvey C, ZuWallack R, Nici L, Rochester C, et al. An official American Thoracic Society/European Respiratory Society statement: key concepts and advances in pulmonary rehabilitation. Am J Respir Crit Care Med 2013;188(8):e11-e40.
2. Bourbeau J, Nault D, Dang-Tan T. Self-management and behaviour modification in COPD. Patient Educ Couns 2004;52(3):271-277.
3. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns 2002;48(2):177-187.
4. McCarthy B, Casey D, Devane D, Murphy K, Murphy E, Lacasse Y. Pulmonary rehabilitation for chronic obstructive pulmonary disease. Cochrane Database Syst Rev 2015;2:CD003793.
5. Osborne R, Elsworth G, Whitfield K. The Health Education Impact Questionnaire (HEIQ): an outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. Patient Educ Couns 2007;66(2):192-101.
6. Hyland M, Jones R, Hanney K. The lung information needs questionnaire: development, preliminary validation and findings. Respir Med 2006;100(10):1807-1816.
7. Sullivan M, LaCroix A, Russo J, Katon WJ. Self-efficacy and self-reported functional status in coronary heart disease: a six-month prospective study. Psychosom Med 1998;60(4):473-478.
8. Jones R, Wang X, Harding S, Bott J, Hyland M. Educational impact of pulmonary rehabilitation: Lung Information Needs Questionnaire. Respir Med 2008;102(10):1439-1445.
9. Vincent E, Sewell L, Wagg K, Deacon S, Williams J, Singh S, et al. Measuring a change in self-efficacy following pulmonary rehabilitation: an evaluation of the PRAISE tool. Chest 2011;140(6):1534-1539.
10. Rijken M, Heijmans M, Jansen D, Rademakers J. Developments in patient activation of people with chronic illness and the impact of changes in self-reported health: results of a nationwide longitudinal study in the Netherlands. Patient Educ Couns 2014;97(3):383-390.
11. Hibbard J, Mahoney E, Stock R, Tusler M. Do increases in patient activation result in improved self-management behaviors? Health Serv Res 2007;42(4):1443-1463.
12. Insignia Health. Patient activation measure (PAM) 13. 2011.
13. Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M. Measuring patient activation in The Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13). BMC Public Health 2012;12:577.
14. Koolen N, van 't Hul A, van der Wees P, Dekhuijzen R, Westert G, Heijdra Y. Activation for self-management in asthma or COPD patients referred to a pulmonologist. Eur Respir J 2017;50:PA3672.
15. Bischoff E, Hamd D, Sedeno M, Benedetti A, Schermer TR, Bernard S, et al. Effects of written action plan adherence on COPD exacerbation recovery. Thorax 2011;66(1):26-31.
16. Bucknall C, Miller G, Lloyd S, Cleland J, McCluskey S, Cotton M, et al. Glasgow supported self-management trial (GSuST) for patients with moderate to severe COPD: randomized controlled trial. BMJ 2012;344:e1060.
17. Turner A, Anderson J, Wallace L, Kennedy-Williams P. Evaluation of a self-management programme for patients with chronic obstructive pulmonary disease. Chron Respir Dis 2014;11(3):163-172.
18. Roberts N, Kidd L, Dougall N, Patel I, McNarry S, Nixon C. Measuring patient activation: the utility of the Patient Activation Measure within a UK context: results from four exemplar studies and potential future applications. Patient Educ Couns 2016;99(10):1739-1746.
19. Eikelenboom N, van Lieshout J, Jacobs A, Verhulst F, Lacroix J, van Halteren A, et al. Effectiveness of personalised support for self-management in primary care: a cluster randomised controlled trial. Br J Gen Pract 2016;66(646):e354- e361.
20. McNamara R, Kearns R, Dennis S, Harris M, Gardner K, McDonald J. Knowledge, skill, and confidence in people attending pulmonary rehabilitation: a cross-sectional analysis of the effects and determinants of patient activation. J Patient Exp 2019;6(2):117-125.
21. Federa. The Code of Conduct for the Use of Data in Health Research. 2004. Available at: https://www.federa.org/codes-conduct. *Accessed March 26, 2021.*
22. World Health Organization. Handbook for good clinical research practice (GCP): Guidance for implementation. 2002: 129. Available at: https://www.who.int/medicines/areas/quality_safety/safety_efficacy/gcp1.pdf. *Accessed March 26, 2021.*
23. Pool G, Heuvel F, Ranchor A, Sanderman R. Handboek psychologische interventies bij chronisch-somatische aandoeningen [Handbook psychological interventions in chronic somatic disorders]. Assen, The Netherlands: Koninklijke van Gorcum; 2004:650.

24. Miller W, Rollnick S. Meeting in the middle: motivational interviewing and self-determination theory. Int J Behav Nutr Phys Act 2012;9 (1):25.
25. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. Health Serv Res 2005;40(6 Pt 1):1918-1930.
26. Osborne R, Batterham R, Elsworth G, Hawkins M, Buchbinder R. The grounded theory, psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). BMC Public Health 2013;13 (1):658.
27. Palange P, Ward S, Carlsen K, Casaburi R, Gallagher C, Gosselink R, et al. Recommendations on the use of exercise testing in clinical practice. Eur Respir J 2007;29(1):185-109.
28. Bestall J, Paul E, Garrod R, Garnham R, Jones P, Wedzicha J. Usefulness of the Medical Research Council (MRC) dyspnoea scale as a measure of disability in patients with chronic obstructive pulmonary disease. Thorax 1999;54(7):581-586.
29. Wijkstra P, ten Vergert E, van Altena R, Otten V, Postma D, Kraan J, Koëter G. Reliability and validity of the Chronic Respiratory Questionnaire (CRQ). Thorax 1994;49(5):465-467.
30. Jaeschke R, Singer J, Guyatt G. Measurement of health status: ascertaining the minimal clinically important difference. Control Clin Trials 1989;10(4):407-415.
31. Spinhoven P, Ormel J, Sloekers P, Kempen G, Speckens A, Van Hemert A, van Hemert A. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. Psychol Med 1997;27(2):363-370.
32. Smid D, Franssen F, Houben-Wilke S, Vanfleteren L, Janssen D, Wouters E, Spruit M. Responsiveness and MCID estimates for CAT, CCQ, and HADS in patients with COPD undergoing pulmonary rehabilitation: a prospective analysis. J Am Med Dir Assoc 2017;18(1):53-58.
33. Puhan M, Frey M, Büchi S, Schünemann H. The minimal important difference of the hospital anxiety and depression scale in patients with chronic obstructive pulmonary disease. Health Qual Life Outcomes 2008;6(1):46.
34. Cohen J. Statistical Power Analysis for the Behavioral Sciences. Hillsdale, NJ: L. Erlbaum Associates; 1988: 567.
35. Bringsvor H, Langeland E, Frøysland Oftedal B, Skaug K, Assmus J, Berit Bentsen S. Effects of a COPD self-management support intervention: a randomised controlled trial. Int J Chron Obstruct Pulmon Dis 2018;13:3677-3688.
36. Nolan C, Patel S, Barker R, George P, Cullinan P, Maher T, et al. Are there differences in response to pulmonary rehabilitation (PR) in idiopathic pulmonary fibrosis (IPF) and COPD patients? Eur Respir J 2017;50:PA4910.