Title

Pulmonary rehabilitation improves self-management ability in subjects with obstructive lung disease

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Abstract

Background: Optimizing self-management is a key element in multidisciplinary pulmonary rehabilitation (PR) in subjects with asthma or chronic obstructive pulmonary disease (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 outpatient PR program. Measures of self-management included the Patient Activation Measure (PAM), the Health Education Impact Questionnaire (HEIQ) (8 subscales), a Self-Efficacy (SE) questionnaire (2 subscales), the Lung Information Needs Questionnaire (LINQ) and the Health Literacy Questionnaire (HLQ) (9 subscales). Mean differences with 95% confidence interval and effect sizes (ES) were computed.

Results: 70 subjects (62.9% women) were included, with a median age of 63.5 years and most of them have been diagnosed with COPD (77%). Between admission and discharge all measures of self-management increased significantly, except for the HEIQ subscales Constructive attitudes and approaches; Social integration and support; and Health services navigation; and the HLQ subscale Social support for health. The largest improvements (effect size >0.55) were seen for the PAM (0.57); the HEIQ subscales Health directed behavior (0.71), Self-monitoring and insight, (0.62) and Skill and technique acquisition (1.00); and the HLQ subscales Having sufficient information to manage my health (1.21) and Actively managing my health (0.66); and the LINQ (1.85).

Conclusion: Self-management, including activation, improves significantly in subjects with asthma or COPD taking part in a multidisciplinary pulmonary rehabilitation program.

Practice Implications: The PAM can be an responsive instrument to evaluate the effects of a pulmonary rehabilitation program in subjects with asthma or COPD.

Key words: Self-management, Patient activation, Chronic obstructive pulmonary disease, COPD, Asthma, pulmonary rehabilitation.

Introduction

For symptomatic subjects with moderate to severe obstructive lung diseases, like chronic obstructive pulmonary disease (COPD) or asthma, pulmonary rehabilitation (PR) is recommended to become a part of routine care [1]. Optimizing subject'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, amongst others, having a personalized action plan and knowing how to use it, being able to ask questions to health care providers, to set goals and make decisions [3].
Regarding the effectiveness of PR programs in subjects with obstructive lung diseases, significant and clinically relevant improvements in dyspnea, fatigue, emotional function, subjects' sense of control over their condition and exercise capacity were found in a systematic literature review including 65 randomized controlled trials [4]. To what extent 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 for the different aspects related to self-management available, either or not specifically for subjects with asthma or COPD, such as the Health Education Impact Questionnaire (HEIQ), the Self Efficacy (SE) questionnaire, or the Lung Information Needs Questionnaire (LINQ) [5-8]. A previous evaluation study did show a significant improvement in self efficacy after PR, measured with the PRAISE Tool [9].
A relatively new concept in this respect is 'patient activation', or readiness to self-manage. This concept of patient activation can be measured using the Patient Activation Measure (PAM)-13 questionnaire, which distinguishes four levels of activation. A higher level implicates more activation to engage in self-management behavior [10-13]. Previous literature demonstrated 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 degree of activation (PAM level 1 or 2) [14]. This is in agreement with the observation that about 40% of the subjects with COPD are capable to perform adequate self-management behavior with regards 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 (n=105) and a

retrospective study (n=38) in subjects with COPD, a statistically significant increase in PAM-score six months after a six–to-seven weeks self-management intervention was seen [17,18]. Subjects with improved PAM-scores showed 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, outpatient 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.

Methods

Study design

This longitudinal study used an observational design. It concerned the 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 (CCMO), this type of study does not require approval from an ethics committee [21] and no informed consent was necessary since the data that was used in this study was collected as a part of usual care. The local Research Review Board of Basalt granted approval of this study. The conduct of the current study was done in accordance with the guidelines for good research practice and guidelines of the Declaration of Helsinki [22].

Subjects

The analysis concerned consecutive subjects who were referred to this outpatient PR program between March 2016 and July 2017, except for those who could not complete questionnaires due to insufficient reading and/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 minutes) three 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 appendix I.

The psychological basis of the program lies in the so called stress-coping model [23]. In order 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 and disease characteristics

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 in the first consultation.

Measures of self-management

Patient Activation

The subjects' level of patient activation was measured with the Patient Activation Measure (PAM-13). This 13-item questionnaire has 5-point Likert answering scales. 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 0-100, which lead to a level of 1-4 [12]. Level one corresponds to the lowest level of activation, subjects are passive and lack confidence, their perspective is "My doctor is in charge of my health", where level four is the highest level subjects can reach, they have adopted

new behaviors but may struggle in times of stress or change [12,13,25]. An improvement of 4 points or more on the PAM total score is considered a meaningful change [17].

Education impact

The subjects' dealing with the disease, or self-management, on a daily basis was measured using the Health Education Impact Questionnaire (HEIQ) [5]. The questionnaire consists of 40 questions which can be answered using a four-point rating scale, resulting in scores in eight different domains, no sum score can be computed. Higher scores imply better self-management abilities.

Health literacy

Using the Health Literacy Questionnaire (HLQ), the subjects' ability to find their way in the healthcare system and skills to manage their health was measured. The questionnaire consists of nine domains. Higher scores imply better skills regarding the specific domain [26].

Information needs

In order 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 (MCID) suggests a change of minus one point to be relevant for subjects with COPD [27].

Self-efficacy

To measure a subject's self-efficacy, the self-efficacy questionnaire by Sullivan was used (SE Sullivan) [7]. The questionnaire consists of 13 items, two separate total-scores can be calculated: 'controlling symptoms' and 'maintaining function'. Lower scores imply more confidence and self-efficacy.

Physical and emotional measures

Exercise capacity

A cardiopulmonary exercise test (CPET) was performed following the ERS/ATS recommendations [28]. Outcome measures were maximum load (watts and percent of predicted) and maximal oxygen

uptake (VO2max). When subjects had severe to very severe COPD (GOLD III/IV) a sub-maximal constant work rate test (CWRT) was done. This test was performed at 75% of peak work rate achieved in the CPET, with cycle time (sec) as main outcome.

Health related quality of life and perceived dyspnea

Using the modified Medical Research Council (mMRC)-score the amount of dyspnea as experienced by subjects was measured. The mMRC-score is a five-point rating score [29]. A higher score implies more dyspnea. Disease specific health related quality of life was measured using the Chronic Respiratory disease Questionnaire (CRQ) [30]. The CRQ comprises 20 questions, which can be summarized into four domains. Higher scores imply a better quality of life. A ten point difference on the total score is the MCID in patients with COPD [31].

Anxiety and depression

The Hospital anxiety and depression scale (HADS) consists of two seven-item scales, one for anxiety and one for depression [32]. The questionnaire is used as a screening tool, where higher scores indicate more complaints. When a subject scores 11-21 points there is probable depression or anxiety [33]. The MCID in patients with COPD was estimated to be around 1.5 points [34].

Analyses

The IBM SPSS Statistics 22 package was used, employing descriptive and inferential statistics to present the data [35]. 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% confidence interval (95% CI) were computed. Additionally, the d-type effect size (ES) was calculated (where 0.2 represents a small effect, 0.5 a medium and 0.8 a large effect) [36].

Results

Baseline characteristics

Between March 2016 and July 2017, 108 subjects diagnosed with asthma and/or COPD were referred to PR. As shown in figure 1, 24 subjects did not meet the inclusion criteria for the outpatient PR, out of the 84 subjects who completed the initial assessment 77 started the PR program. Seven subjects dropped out during the program, therefore a total of 70 subjects completed the program. Table 1 displays the characteristics of both these groups.

The median age of the subjects who completed the program was 63.5 years (range 29 to 84 years), and 26 (37.2%) were male. The majority of the subjects had COPD (54 subjects, 77.1%) and had one to two 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 as shown in table 2, they significantly differed in smoking status, pack years, level of education, lung function, BMI, exercise capacity measured with CPET and mMRC. 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 four points. Figure 2 shows the changes in PAM levels. The majority of the subjects improved in PAM level, 24 (41%) subjects improved one level and 7 (12%) subjects displayed an increase of two levels.

All outcome measures for self-management showed statistically significant improvements over time, except for the HLQ 4 and the HEIQ 5, 7 and 8. Effect sizes were medium for the PAM (0.57), the HEIQ 1 (0.71), 4 (0.62) and the HLQ 3 (0.66), 6 (0.50), 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 VO2max, subjects showed a statistically significant improvement ($p \leq 0.01$). 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 non-responders (n=25, 45%). All subjects with a PAM level 4 score at initial assessment (n=3) also scored a PAM 4 at discharge, they were excluded from the analysis due to ceiling effect and therefore no room to respond. Out of the 25 non-responders, 14 subjects (56%) scored an initial PAM level 3, with the remaining patients scoring level 1 or 2 (respectively n=6 (24%) and n=5 (20%)). For the responders, the number of patients scoring level 3 at initial assessment was only 16% (n=5), with respectively n=14 (45%) and n=12 (39%) scoring level 1 or 2. Table 5 presents the mean differences in outcomes between the responders and the non-responders at discharge. The mean change in PAM score, LINQ score and various domains of the HEIQ and HLQ differ significantly (≤0.05). Responders show a significantly greater decline in information needs than the non-responders (mean difference -3.18 (-5.05 ; -1.31), p = 0.00). 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 non-responders significant improvements were seen for 9 out 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 the literature demonstrating an 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, and HLQ 2, and SE-CS (all ES ≥ 0.8). Subscales regarding social support (HEIQ 7, HLQ 4) did not display a significant improvement. This could be due to the fact that the program more strongly emphasizes the subjects' knowledge, behavior and physical capacity than it addresses the subjects' caregivers and social environment.

Bringsvor et al. [37] conducted a RCT evaluating the effects of a self-management intervention 'Better living with COPD', which consisted of weekly two-hour-long group conversations over 11 weeks compared with usual care. Different outcome measures were used, amongst others the HEIQ which displayed a significant but smaller improvement compared to our study. The largest improvements were seen in the domains HEIQ 4, HEIQ 5 and HEIQ 6, with 0.38 as the largest effect size. Our findings display effect sizes in five out of eight HEIQ domains with an ES up to 1.0. A reason for these differences could be the fact that Bringsvor et al. [37] did not include exercise in their intervention, which seems to be related to HEIQ 1, in which we saw a significant improvement (ES 0.71).

The LINQ has been studied in a few other studies as well. Jones et al. [8] and Nolan et al. [38] also demonstrated that the LINQ improves with PR, but in comparison, we found a greater improvement with an ES of 1.85 compared to 0.74.This may be due to the fact that the program that was offered was in the study by Nolan was limited to an outpatient-based program which took place twice a week (one hour exercise training and one hour of education) for eight weeks with an unsupervised exercise session at home, which seems significantly less intensive than our 12-week PR program. Baseline LINQ, mMRC and CRQ measures were comparable to this study. The PR program described by Jones was also more limited, the number of sessions differed between one and three sessions a week, during approximately two hours and consisted of exercise and/or education. 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 outpatient PR program consisting of 16 sessions of 1-hour supervised individualized exercise training and structured education sessions delivered in a group setting by a team of multidisciplinary health professionals in Australia on the PAM and LINQ and they also described improvements in these outcomes, but less extensive than our study does (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 healthcare professionals who had group sessions and one-to-one sessions, tailoring the PR program to the needs of the subjects (Appendix I).

Turner et al. [17] executed 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 four 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 Turner's study. Also, our program was more extensive, guided only by professionals, and lasted several weeks longer, possibly explaining the difference in response.

When looking at differences between responders and non-responders, it is striking that there were no significant differences in quality of life, exercise tolerance and/or dyspnea between these groups. As previously suggested, higher PAM scores would imply a better quality of life. However, since pulmonary rehabilitation is a comprehensive program, there are more factors involved that can affect the subjects' quality of life such as psychological support, and not only the improvement in activation. An outcome like exacerbation management or healthcare utilization was 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 score level in responders versus non-responders, it clearly shows that the non-responders have higher initial scores, an 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 subject to fill out 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 respectively eight and nine different domain scores, without a sum score, which are less clear and insightful for clinicians in daily practice where time is precious. Measuring a subject's level of activation can be of great value to customize the care that is provided. Subjects who score low on activation might need a different approach compared to subjects with a high PAM score and therefore more skills 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 subject already has.

This study has some methodological considerations. First, it had an observational design. There was no usual care control group to compare this group of subjects with 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 subjects' home address at the time, where they could fill in the forms. Despite several checks there were some missing data. Finally, the current study design does not allow to determine the active ingredients of the multidisciplinary PR program that have contributed to the improvements in self-management and patient activation. However, it seems reasonable that the fact that this concerns a comprehensive, outpatient, multidisciplinary pulmonary rehabilitation 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 two moments in time where the measurements were done. Up to date there is only one other study [20] that has examined changes over time in subjects with asthma or COPD following PR program combining exercise and education, but the subjects in that study had notable 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 the level of activation, and 62% of the subjects in PAM level 1 or 2, our group of subjects scored even lower than in other groups described in previous literature, possibly implying an even more severe burden of disease.

Conclusion

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

Practice implications

The PAM can be an effective instrument to evaluate the effects of a pulmonary rehabilitation program in subjects with asthma or COPD. This instrument can also be used by clinicians in daily practice to

gain insight in a subject's level of activation in order to customize and tailor their treatment for optimal results.

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Quick look

Current knowledge

Optimizing self-management is a key element in multidisciplinary pulmonary rehabilitation (PR) in subjects with asthma or chronic obstructive pulmonary disease (COPD). 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.

What this paper contributes to our knowledge

The value of this manuscript is especially its emphasis on the outcome patient activation, combined with other measures of self-management and the positive changes we have found over time. Self-management is an key element of pulmonary rehabilitation but up to date no evident studies regarding the effect of a multidisciplinary pulmonary rehabilitation program on this subject have been done.

Figure 1, Flowchart of inclusion of subjects in the pulmonary rehabilitation (PR) program.

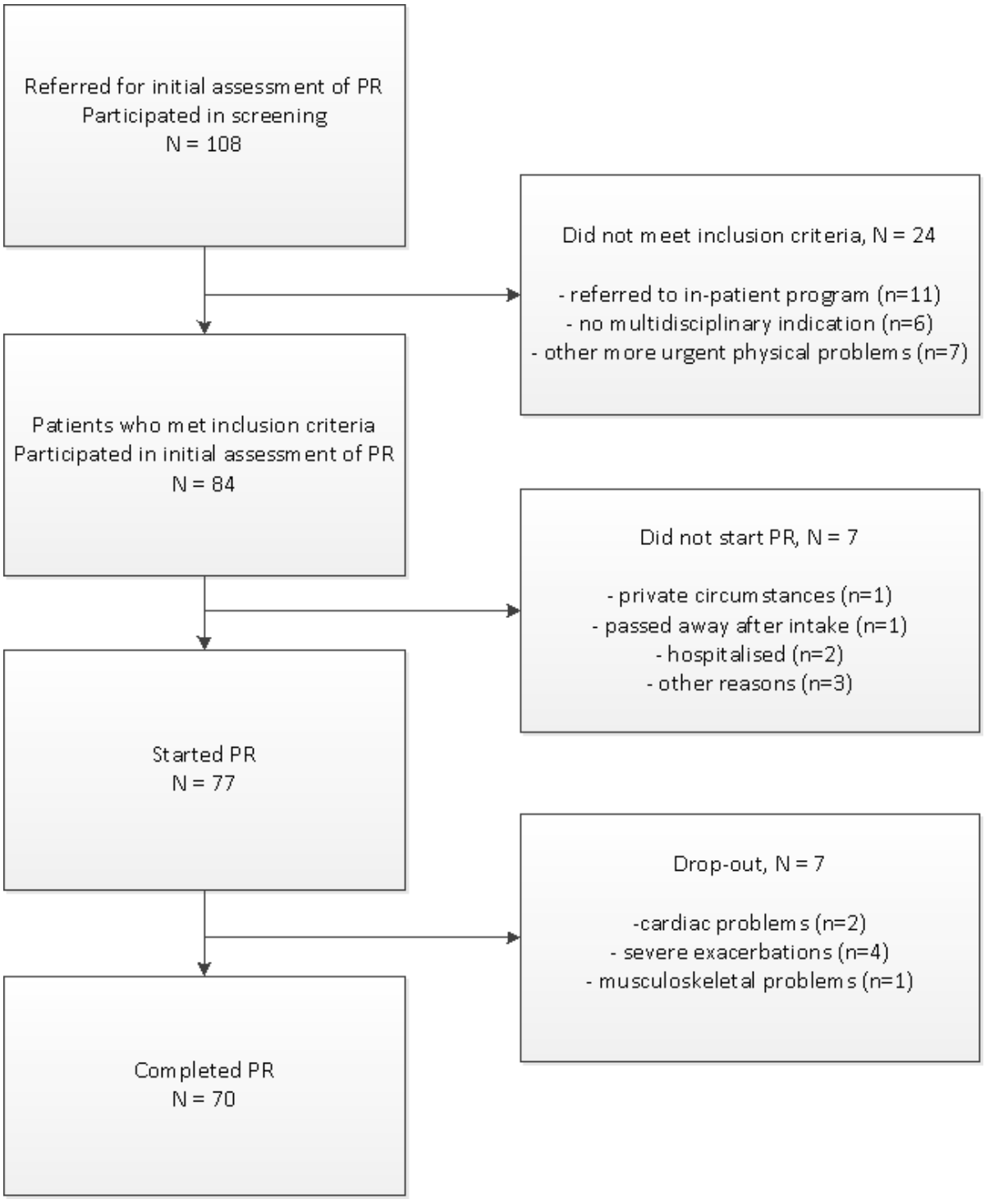

Figure 2, Number of subjects and the shift in PAM level from initial assessment to discharge (total n=59).
Flow lines indicate the changes in PAM level, with the number of subjects in the lines.
The thickness of the line is related to the number of subjects.

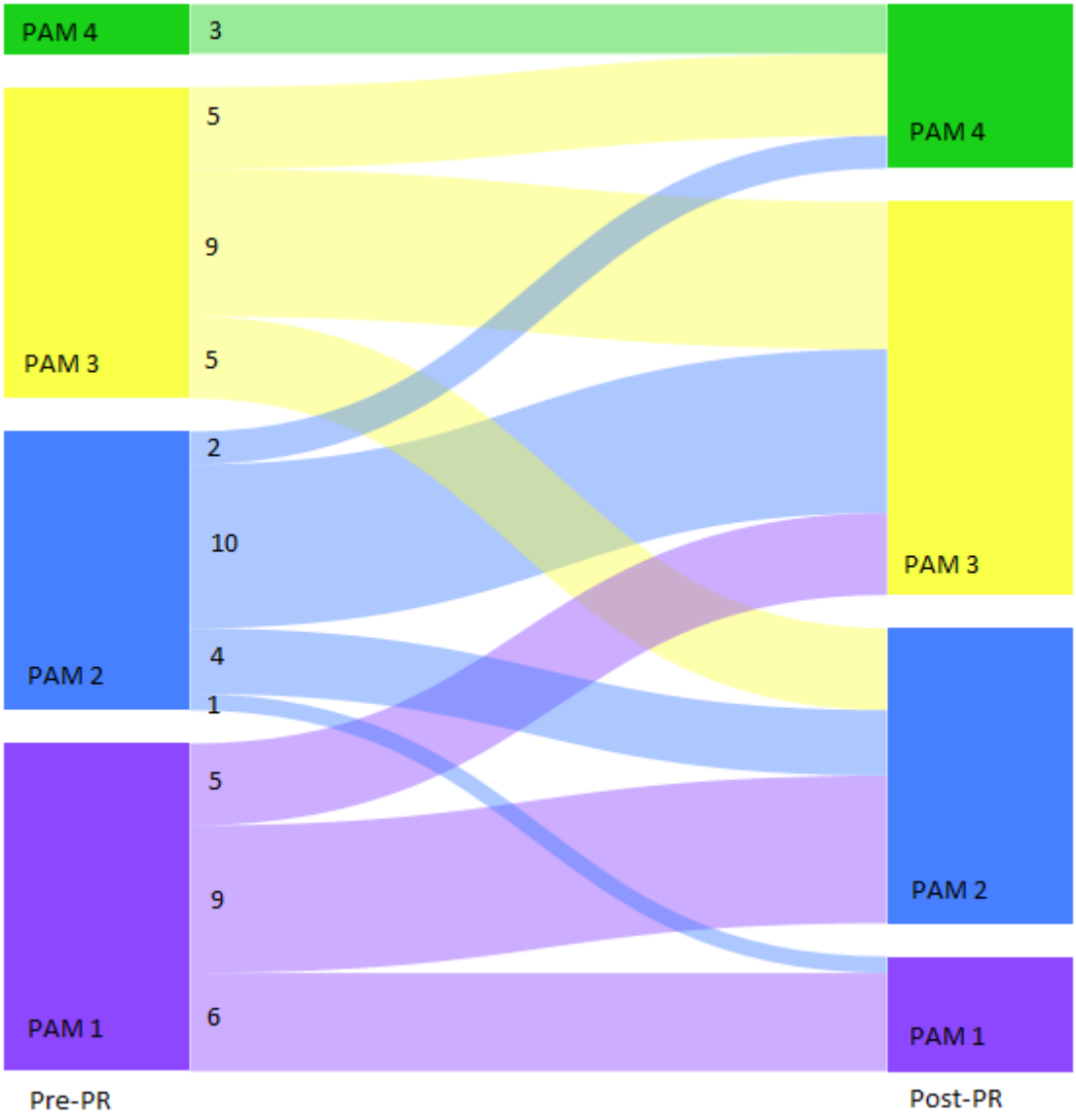

Table 1, Characteristics of subjects with asthma or COPD who did and did not complete the pulmonary rehabilitation program.
Data are reported as median (min-max range), or number (%).

	Subjects who completed the program (n=70)	**Subjects who did not complete the program (n=7)**
Sex, male	26 (37%)	2 (29%)
Age, years	64 (29 – 84)	68 (58 – 78)
Level of education Low High	 43 (67%) 21 (33%)	 4 (67%) 2 (33%)
Living arrangements, living alone	24 (34%)	4 (57%)
BMI (kg/m^2) *	26 (17 – 49)	19 (17 – 26)
Diagnosis (asthma / COPD) *	16 (23%) / 54 (77%)	0 / 7 (100%)
Gold stadium I II III IV	 0 13 (24%) 30 (56%) 11 (20%)	 0 0 5 (71%) 2 (29%)
FEV1/VC *	40 (22 – 82)	33 (19 – 41)
FEV1 (% predicted)	43 (22 – 116)	38 (16 – 53)
Smoking status Current smoker Stopped smoking (<4 weeks) Never smoked	 14 (20%) 48 (69%) 8 (11%)	 1 (14%) 6 (86%) 0
Pack years, in smokers	35 (0 – 100)	36 (20 – 55)
Number of comorbidities ** 0 1-2 >2	 13 (19%) 39 (56%) 18 (26%)	 1 (14%) 2 (29%) 4 (57%)
Number of exacerbations in the past 12 months 0 1-2 >2	 14 (20%) 28 (41%) 27 (39%)	 1 (14%) 3 (43%) 3 (43%)
Number of lung-related hospital admissions in the past 12 months 0 1-2 >2	 45 (71%) 14 (22%) 4 (6%)	 5 (71%) 0 2 (29%)

*p≤0.05

**Diabetes, hypertension, myocardial infarction, heart failure, arrhythmia, CVA, lung cancer, osteoporosis, obesity, underweight, anxiety, depression, coronary artery disease and/or peripheral vascular disease.

Abbreviations: BMI, body mass index; COPD, chronic obstructive pulmonary disease; FEV 1 , forced expiration volume in 1 second; FEV 1 /VC, ratio between forced expiration volume in 1 second and vital capacity

Level of education; Low = primary/lower vocational education/secondary education/intermediate vocational education; high = higher vocational education/university.

Table 2, baseline COPD vs asthma.
Data are reported as median (min-max range), mean ±SD, or number (%).

N=70	**COPD (n = 54)**	**Asthma (n = 16)**	**p**
Sex, male	22 (41%)	4 (25%)	0.25
Age *	66 ± 9	54 ± 14	0.00
Living arrangements, living alone	19 (35%)	5 (31%)	0.77
Number of exacerbations in the past 12 months			
0	10 (19%)	4 (25%)	
1-2	22 (42%)	6 (38%)	
>2	21 (40%)	6 (38%)	0.97
Number of lung-related hospital admissions in the past 12 months			
0	33 (69%)	12 (80%)	
1-2	11 (23%)	3 (20%)	
>2	4 (8%)	0 (0%)	0.77
Smoking status *			
Never smoked	0 (0%)	8 (50%)	
Current smoker	14 (26%)	0 (0%)	
Stopped smoking (<4 weeks)	40 (74%)	8 (50%)	0.00
Pack years, in smokers *	40 (10 – 100)	0 (0 -42)	0.00
mMRC *	3 (1 – 5)	3 (2 – 4)	0.02
CRQ som	80 ± 19	76 ± 18	0.46
Level of education *			
Low	38 (76%)	5 (36%)	
High	12 (24%)	9 (64%)	0.00
LINQ	10 ± 3	9 ± 4	0.62
PAM score	51 (32 – 91)	51 (41 – 73)	0.90
PAM level			
1	17 (33%)	6 (40%)	
2	15 (30%)	3 (20%)	
3	17 (33%)	5 (33%)	
4	2 (4%)	1 (7%)	0.87
Self-efficacy Control Symptoms	21 (9 – 38)	19 (10 – 33)	0.64
Self-efficacy Maintain Function	8 (3 – 13)	8 (5 – 14)	0.20
HADS: Anxiety	6 (0 – 17)	6 (0 – 15)	0.60
HADS: Depression	6 (1 – 15)	5 (2 – 14)	0.51
FEV1 *	1.1 (0.5 – 2.4)	1.9 (0.8 – 3.9)	0.00
FEV1 % *	41 (22 – 71)	80 (27 – 116)	0.00
FEV1/VC *	37 (22 – 59)	61 (32 – 82)	0.00
FEV1/VC % *	45 (30 – 77)	80 (44 – 96)	0.00
BMI *	25 (17 – 36)	31 (24 – 49)	0.00
FFM-I	14 (12 – 17)	16 (n=1)	0.40
Number of comorbidities			
0	10 (19%)	3 (19%)	
1-2	30 (56%)	9 (56%)	
>2	14 (26%)	4 (25%)	0.81
Peak exercise capacity (% predicted) *	39 (9 – 112)	77 (30 – 127)	0.00
CWRT (sec)	587 (60 – 900)	639 (377 – 900)	0.84

* p≤0.05

Table 3, Outcomes in patient activation, education impact, health literacy, information needs, self-efficacy and rehabilitation outcomes in subjects completing pulmonary rehabilitation.
Data are reported as median (min-max range), mean ± SD, or number (%).

N = 70		Initial assessment	Discharge	Mean Difference (95% CI)	Effect Size	Missing
Patient Activation Measure (PAM)						
PAM score	*	51 (32 – 91)	56 (44 – 100)	7 (4 – 10)	0.57	11
PAM level 1 PAM level 2 PAM level 3 PAM level 4	*	23 (35%) 18 (27%) 22 (33%) 3 (5%)	7 (12%) 19 (31%) 24 (39%) 11 (18%)			11
Health Education Impact Questionnaire (HEIQ)						
HEIQ 1, health directed behaviour	*	2.6 (1 – 4)	3 (1.3 – 4)	0.4 (0.3 – 0.5)	0.71	8
HEIQ 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
HEIQ 3, emotional well-being	*	2.8 (1.3 – 4)	3 (1.5 – 4)	0.2 (0.7 – 0.3)	0.34	8
HEIQ 4, self-monitoring and insight	*	2.8 (1.8 – 4)	3 (2.5 – 4)	0.3 (0.1 – 0.4)	0.62	8
HEIQ 5, constructive attitudes and approaches		3 (2 – 4)	3 (2 – 4)	0.1 (-0.0 – 0.3)	0.22	8
HEIQ 6, skill and technique acquisition	*	2.5 (1.8 – 4)	3 (1 – 4)	0.4 (0.3 – 0.5)	1.00	8
HEIQ 7, social integration and support		3 (1.2 – 4)	3 (1 – 4)	0.1 (-0.0 – 0.2)	0.20	8
HEIQ 8, health services navigation		3 (1.8 – 4)	3 (2 – 4)	0.1 (-0.1 – 0.2)	0.21	8
Health Literacy Questionnaire (HLQ)						
HLQ 1, Feeling understood and supported by healthcare providers	*	3 (1 – 4)	3 (1.8 – 4)	0.2 (0.1 – 0.4)	0.43	10
HLQ 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
HLQ 3, Actively managing my health	*	2.6 (1.4 – 4)	3 (1.8 – 4)	0.3 (0.2 – 0.4)	0.66	10
HLQ 4, Social support for health		2.8 (1.2 – 3.6)	3 (1.2 – 4)	0.1 (-0.2 – 0.2)	0.14	10
HLQ 5, Appraisal of health information	*	2.4 (1.2 – 4)	2.8 (1.6 – 4)	0.2 (0.1 – 0.4)	0.47	10
HLQ 6, Ability to actively engage with healthcare providers	*	3.6 (1.6 – 5)	4 (2.4 – 5)	0.3 (0.1 – 0.4)	0.42	10
HLQ 7, Navigating the healthcare system	*	3.3 (1.7 – 5)	3.7 (2.5 – 5)	0.3 (0.2 – 0.5)	0.50	10
HLQ 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
HLQ 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
Information needs						
Lung Information Needs Questionnaire (LINQ)	*	9.8 ± 3.4	4.2 ± 2.6	-5.5 (-6.5; -4.5)	1.85	11
Self-efficacy						
Self-efficacy Control Symptoms	*	21 (9 - 38)	17 (7 – 26)	-4.4 (-5.9; -2.8)	0.79	8
Self-efficacy Maintain Function	*	8 (3 - 14)	7 (2 – 11)	-1.1 (-1.7; -0.4)	0.40	8

* p≤0.05

Table 4, Physical and emotional outcomes in subjects completing pulmonary rehabilitation.
Data are reported as median (min-max range), mean ± SD, or number (%).

N = 70	**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 (% predicted) *	46 (9 - 127)	63 (23 – 143)	6 (2–10)	0.19	30
Maximal oxygen uptake (VO2max (ml/min))	1195 ± 398	1395 ± 454	41 (-36– 119)	0.09	34
Maximal oxygen uptake (VO2 max (% predicted))	73 ± 26	80 ± 26	2 (-3 – 6)	0.06	34
CWRT (sec) *	506 (60 - 900)	640 (145 – 900)	171 (44 – 297)	0.61	54
Perceived dyspnoea and quality of life					
Modified Medical Research Council dyspnea scale *	3 (1 - 5)	3 (1 – 5)	-1 (-1; -0)	0.44	8
Chronic Respiratory Disease Questionnaire *	80 ± 19	98 ± 19	18 (14– 22)	0.99	8
Anxiety and depression					
Hospital Anxiety and Depression Scale: Anxiety *	6 (0 – 17)	4 (0 – 13)	-2 (-3; -1)	0.39	8
Hospital Anxiety and Depression Scale: Depression *	6 (1 – 15)	4 (0 – 14)	-1 (-2; -1)	0.38	8

* p≤0.05

Table 5, Change scores of various outcome measures in responders and non-responders as well as differences in change scores
Data are reported as mean difference (95% CI).
Subjects who scored a PAM 4 at baseline (n=3) were excluded form analysis due to ceiling effect and therefore no room to respond.

	Responders n = 31	**Non-Responders n = 25**	**Mean Difference (95% CI)**	**p-value**
Patient Activation Measure (PAM)				
PAM score *	12.9 (10.0 ; 15.9) **	-1.5 (-4.4 ; 1.4)	14.5 (10.3 ; 18.6)	≤0.001
Health Education Impact Questionnaire (HEIQ)				
HEIQ 1, health directed behaviour	0.4 (0.3 ; 0.6) **	0.4 (0.2 ; 0.6) **	0.0 (-0.2 ; 0.3)	0.80
HEIQ 2, positive and active engagement in life	0.2 (0.1 ; 0.3) **	0.01 (-0.1 ; 0.3)	0.1 (-0.1 ; 0.3)	0.30
HEIQ 3, emotional well-being	0.3 (0.2 ; 0.5) **	0.1 (-0.1 ; 0.4)	0.2 (-0.1 ; 0.4)	0.17
HEIQ 4, self-monitoring and insight *	0.4 (0.2 ; 0.5) **	0.1 (-0.1 ; 0.3)	0.3 (0.1 ; 0.5)	0.02
HEIQ 5, constructive attitudes and approaches	0.2 (0.0 ; 0.4) **	0.0 (-0.2 ; 0.2)	0.2 (-0.1 ; 0.5)	0.13
HEIQ 6, skill and technique acquisition *	0.5 (0.4 ; 0.6) **	0.2 (0.1 ; 0.3) **	0.3 (0.1 ; 0.5)	0.01
HEIQ 7, social integration and support	0.2 (0.1 ; 0.3) **	0.1 (-0.2 ; 0.2)	0.1 (-0.1 ; 0.4)	0.22
HEIQ 8, health services navigation *	0.3 (0.1 ; 0.4) **	-0.2 (-0.4 ; 0.0)	0.4 (0.2 ; 0.7)	≤0.001
Health Literacy Questionnaire (HLQ)				
HLQ 1, Feeling understood and supported by healthcare providers *	0.3 (0.1 ; 0.5) **	-0.0 (-0.2 ; 0.1)	0.3 (0.1 ; 0.6)	0.01
HLQ 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)	≤0.001
HLQ 3, Actively managing my health	0.4 (0.2 ; 0.5) **	0.2 (0.1 ; 0.4) **	0.1 (-0.1 ; 0.3)	0.24
HLQ 4, Social support for health *	0.12 (0.0 ; 0.3) **	-0.1 (-0.2 ; 0.1)	0.2 (0.0 ; 0.4)	0.03
HLQ 5, Appraisal of health information	0.3 (0.1 ; 0.4) **	0.2 (-0.0 ; 0.3)	0.1 (-0.1 ; 0.3)	0.30
HLQ 6, Ability to actively engage with healthcare providers*	0.4 (0.2 ; 0.6) **	0.1 (-0.3 ; 0.4)	0.4 (-0.0 ; 0.7)	0.04

HLQ 7, Navigating the healthcare system	0.4 (0.3 ; 0.6) **	0.2 (-0.1 ; 0.4)	0.3 (-0.0 ; 0.6)	0.09
HLQ 8, Ability to find good health information	0.3 (0.1 ; 0.5) **	0.3 (0.0 ; 0.6) **	0.1 (-0.3 ; 0.4)	0.72
HLQ 9, Understand health information well enough to know what to do	0.3 (0.1 ; 0.5) **	0.1 (-0.2 ; 0.4)	0.2 (-0.1 ; 0.5)	0.19
Information needs				
LINQ *	-6.7 (-8.1 ; -5.3) **	-3.5 (-4.6 ; -2.4) **	-3.2 (-5.1 ; -1.3)	≤0.001
Self-efficacy				
Self-efficacy Control Symptoms	-5.8 (-7.9 ; -3.8) **	-3.4 (-6.2 ; -0.5) **	-2.5 (-5.8 ; 0.8)	0.14
Self-efficacy Maintain Function	-1.3 (-2.1 ; -0.4) **	-0.8 (-1.9 ; 0.3)	-0.5 (-1.8 ; 0.9)	0.51
Exercise tolerance				
Peak exercise capacity (% predicted)	7.0 (1.5 ; 12.4) **	-1.1 (-6.9 ; 4.8)	8.0 (-0.3 ; 16.4)	0.06
Endurance exercise capacity (sec)	197.3 (-96.6 ; 491.1)	154.0 (3.3 ; 304.7) **	43.3 (-250.8 ; 337.3)	0.75
Perceived dyspnoea and quality of life				
mMRC	-0.6 (-1.0 ; -0.2) **	-0.4 (-0.8 ; 0.1)	-0.2 (-0.8 ; 0.3)	0.41
CRQ	21.0 (14.7 ; 27.3) **	14.2 (7.2 ; 21.1) **	6.8 (-2.4 ; 16.1)	0.14
Anxiety and depression				
Hospital Anxiety and Depression Scale: Anxiety	-2.1 (-3.2 ; -1.0) **	-1.5 (-3.4 ; 0.4)	-0.6 (-2.6 ; 1.5)	0.57
Hospital Anxiety and Depression Scale: Depression	-1.9 (-2.8 ; -1.0) **	-0.6 (-1.6 ; 0.4)	0.7 (-2.7 ; 0.1)	0.06

* p≤0.05, significant differences between groups.

** p≤0.05, significant mean differences in group (initial assessment vs discharge).