Outcome assessment in inpatient pulmonary rehabilitation: clinical results and methodological aspects
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Assessing inpatient pulmonary rehabilitation using the patient's view of outcome

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'Would you tell me, please, which way I should go from here?'
'That depends a good deal on where you want to get go,' said the Cat

Lewis Carroll
Alice in Wonderland, 1865
7.1 Abstract

Purpose: Assessment of the patient's view of outcome should complement standardized evaluation methods, especially in multi-intervention rehabilitation programmes. Assessment of individualized outcomes has not been used previously in pulmonary rehabilitation studies. Therefore we developed a method for assessing the patient's view of outcome. Methods: Patients and their therapists scored the subjective attainment level of individualized treatment goals on a six-point response scale. Mean attainment scores, sensitivity to change, reliability and validity were computed. Results: 79 patients (20 with asthma and 59 with chronic obstructive pulmonary disease) who participated in an inpatient pulmonary rehabilitation program had 540 treatment goals (range 2-12 goals per patient). The patients had a significantly higher median attainment score than the main therapists (5 versus 4, n=286, p<0.0001). Sensitivity to change of the attainment scores from patients was very high. The patients (n=42) had a standardized response mean of 3.57 for the attainment scores, as compared to 1.01 for the total score of the Quality of Life for Respiratory Illness Questionnaire. Attainment scores of treatment goals with at least 10 occurrences were significantly correlated with closely related external outcomes. Inter-rater agreements between patients and therapists as well as among therapists were low (weighted kappa <0.35). Conclusions: The patient’s view was used to describe the outcome of inpatient pulmonary rehabilitation. Attainment scoring has a high sensitivity to change and a satisfying validity. The low reliability between the individual's point of view and that of the therapist necessitate a clear description of the different levels of expected outcome. The individualized goal attainment method seems a promising complementary way of evaluating pulmonary rehabilitation

7.2 Introduction

Patients with asthma or chronic obstructive pulmonary disease (COPD) often experience severe disabilities and handicaps despite optimal medical treatment. Outpatient pulmonary rehabilitation has proven to be an effective treatment in most of these patients [1]. Standard treatment programmes are however not sufficient in severely impaired patients [2] who have an unstable disease pattern and/or a high burden of disease, characterized by frequent hospitalization, a high medication usage, somatic comorbidity and/or severe deconditioning. The somatic severity is often complicated by psychosocial problems such as anxiety, depression, relational and/or occupational problems. Standardized programmes, such as most outpatient and home rehabilitation programmes [3-6], may not meet all the
needs of severely ill patients [7]. A multidisciplinary inpatient pulmonary rehabilitation program (IPR) with treatment goals tailored to the individual and specific problems of a patient may be necessary. However, a multidisciplinary treatment programme consisting of several simultaneous interventions to address the multiple problems of a patient brings about a major problem with usual outcome assessment.

The usual set of outcome measures for studies on pulmonary rehabilitation consists of standardized questionnaires and function tests. Standardized outcome measures have the following major advantages. They represent the most common disabilities and impairments, have been tested for reliability and validity, are suitable for large groups of patients, and allow comparison across studies. Although this approach may work well with standard treatment programmes for well-defined patient groups, it has some important disadvantages. Standardized outcome measures do not allow for the large variation in problems of individual patients and for differences in importance of these problems [8]. Most outcome variables address common problems, but they neither represent the specific problems experienced by an individual patient nor the specific intervention addressing that problem. This may cause misinterpretation of treatment results, both on the level of individual patients and on the level of program assessment. Therefore we think that outcome assessment in pulmonary rehabilitation may be improved by looking at the individual goals of a patient and how the interventions have helped to attain these goals.

As an alternative to measuring outcome with standard tests and questionnaires, we tried to capture the patient’s view of outcome, by asking them to give a subjective assessment of the level of attainment of the individualized treatment goals they aimed to achieve during the IPR treatment. The therapists from the multi-intervention IPR were asked to give a similar assessment for their treatment goals. This assessment was developed as part of a shift from a therapist-centered approach to a more patient-centered approach. In the therapist-centered approach, the therapist set the goal and gave the appropriate treatment to the patient, with each therapist having a separate agreement with the patient about which goals were important to attain. The new method implies a shift to a patient-centered approach in which the patient is actively involved in setting, prioritizing and assessing his or her own treatment goals, all in consultation with the treatment team. This important shift in paradigm should ensure comprehension of the content and rationale of the treatment given and should motivate the patient to participate more actively in the treatment (a key factor for success [7;9]) instead of merely "doing what the doctor told you". The patient’s participation in assessing the intermediate and final treatment results may enhance motivation to comply with the treatment. An additional influence on the shift to a patient-centered approach was the recent Dutch Medical Treatment Contracts Act [1995], which orders caretakers to obtain full informed consent of the patient for the proposed treatment.
A patient should comprehend the treatment goals and approve of them. This is achieved by the patient’s active involvement in goal setting. This study contains a new and complementary method of evaluating IPR and is part of a comprehensive evaluation study that includes all traditional methods of evaluation. Full details about the 'traditional' short- and long-term outcome of IPR in patients with asthma and COPD are described in chapters 2 and 3 of this dissertation.

This paper describes the outcome of IPR as viewed by individualized outcome measurement and can be considered a new and complementary method for evaluating pulmonary rehabilitation.

### 7.3 Methods

#### 7.3.1 Patients

The participants in this study were 79 patients with moderate to severe asthma (n=20) or COPD (n=59) referred for inpatient pulmonary rehabilitation at Asthmacentre Heideheuvel. The main reasons for referral are an unstable disease pattern and/or a high burden of disease, characterized by frequent hospitalization, recurring exacerbations, high medication usage and/or somatic or psychosocial comorbidity.

Patients were included consecutively from March 1997 to December 1998. Patients who did not complete the IPR or did not speak Dutch were excluded from the study. Diagnosis including assessment of disease severity was done by a pulmonologist according to criteria from the European Respiratory Society [10]. All patients gave written informed consent and the study protocol was approved by the institutional medical ethics committee.

#### 7.3.2 Individualized treatment goals

The inpatient programme aims to improve function and quality of daily life. Because patients with severe chronic asthma often experience similar problems as patients with COPD (deconditioning, high symptom burden, inadequate disease behaviour, hospitalizations, high medication usage), the IPR programme is open to both types of patients. The standardised programme with individual adaptations consists of several clinical and psychosocial aspects [7;11]:

- optimization of the medication regimen; education on disease pathophysiology, on the effect of medication, on correct use and inhalation technique of medication (education varying from 1 hour/week for all patients to 2-3 hours/week for patients needing extensive help with use of their medication);
training of adequate disease behaviour and self-management skills, including an
individualized ‘what to do’ list to prevent exacerbations when lung function
decreases or symptoms increase;
• extensive psychosocial counselling (1 to 4 hours/week) including assertiveness
training and cognitive-emotive therapy;
• chest physiotherapy and breathing exercises;
• exercise training with varying intensity depending on the individual tolerance:
exercise training consisted of diverse upper and lower extremity exercises, ranging
from three 30 minute, low intensity sessions a week for patients with very severe
COPD, to five 45’ to 60-minute sessions moderate to high intensity sessions a week
for better patients.

The duration of the IPR ranges from 3 to 6 months, depending on the specific problems
and treatment goals of a patient. Because of the large variation in individual problems and the
essential role of motivation in pulmonary rehabilitation [7], individualized treatment goals
are formulated by the multidisciplinary treatment team in consultation with the patient.
After a one-week multidisciplinary diagnostic phase, an extensive integrated description of
the specific problems of the patient is constructed. Individualized treatment goals, based
on this problem description, are formulated by the treatment team in consultation with the
patient. These treatment goals are expressed in words familiar to the patient to ensure
comprehension of content and maximal motivation. The multidisciplinary treatment team
consists of a pulmonologist, respiratory nurse, psychologist, physiotherapist, exercise
therapist, dietician, social worker, therapeutic recreation specialist and occupational
therapist.

Examples of individual treatment goals are as follows:
• I want to learn what I should do to be less short of breath: by learning what happens
  when I get short of breath; be feeling and recognizing what my body does; by
  learning how to do daily things without getting short of breath;
• I want to move in such a way that I can easily keep on breathing;
• I want to learn my own limits when exercising and learn to take these limits into
  account when doing my daily activities;
• I want to describe the goals of this treatment to my partner; learning to be more
  open about my feelings and learning to listen more carefully to my partner;
• I want to learn to clearly describe my physical situation to others and to come out
  with possible solutions;
• I want to increase my knowledge about medications, so I know how to use them and
  what they are meant for;
patient's view of outcome in pulmonary rehabilitation

- I want to learn to use breathing exercises to intercept shortness of breath so I am able to use a good breathing pattern during both rest and exercise;
- I want to accept that I'm OK the way I am, that I'm allowed to make mistakes, that I can say NO (and may be naughty);
- I want to work out together with my wife which physical activities I still can do at home;
- I want to increase my physical condition so I will remain able to live independently;
- search for adapted housing suitable for electric scooter;
- I want to attain a balance between activities and physical condition, by using a weekly programme;
- I want to recognize my limits and act accordingly, instead of increasing medication;

Categories of individualized treatment goals are placed in the appendix.

The treatment progress of a patient is evaluated every six weeks by the multidisciplinary treatment team. In this study, assessment of whether the individualized treatment goals were attained was accomplished preceding this evaluation. Attainment of a treatment goal was scored by the patient (patient attainment score), by the therapist responsible for that treatment goal (main therapist attainment score) and by therapists, if any, co-operating on that treatment goal (cotherapist attainment score). The therapists assessed only the treatment goals in which they were involved. The main therapist for a treatment goal was determined by the content of the goal. For example, the respiratory nurse would be the main therapist for a treatment goal on correct use of medication. A treatment goal on self-pacing would be a cooperation between the exercise therapist, the physiotherapist and the respiratory nurse, one of which would be the main therapist depending on the situation of the patient. For most patients, it would be the exercise therapist, whereas for a patient in the intensive treatment facility, it would be the respiratory nurse. In addition to the normal exercise training, some patients had an explicit treatment goal of improved exercise tolerance, which meant higher intensity training and more support from the exercise therapist than in normal training.

Attainment scoring was done for each treatment goal by asking on a six-point response scale if the patient did attain that goal: not at all (1), barely (2), a bit (3), partly (4), largely (5), completely (6). A treatment goal was considered successful with a score of 5 or 6; a goal with a score of 3 or 4 was considered partially successful. Only the last attainment score of each treatment goal was used. Treatment goals were assessed throughout the treatment period, at least once, with four times being the maximum. When a treatment goal was successfully reached, a new treatment goal (from the treatment contract, based on the extensive diagnostic description) was started. A treatment goal without improvement would be changed and reformulated by team and patient.
7.3.3 Standard outcome assessment

Of the 79 patients in the study, 42 patients also participated in an outcome study on inpatient pulmonary rehabilitation. Change scores from standardized questionnaires and function tests were used to assess the responsiveness and the longitudinal validity of attainment scoring. Pre-treatment assessments were performed in the diagnostic week preceding the inpatient pulmonary rehabilitation programme. Post-treatment data were collected in the week before discharge. The following external outcome measures were selected. Disease-specific health-related quality of life was measured with the Quality of Life for Respiratory Illness Questionnaire (QoLRIQ), which is designed for both patients with asthma and patients with COPD [12] This self-report questionnaire can be completed in approximately 15 minutes and consists of 55 items divided into seven domains: breathing problems, physical problems, emotions, situations triggering or enhancing breathing problems, general activities, daily and domestic activities, and social activities, relationships and sexuality. The QoLRIQ uses a 7-point response scale; a higher score represents more impairment. The minimal important difference (MID) of the QoLRIQ has been estimated at 0.5 units (see chapter 6 of this dissertation). The QoLRIQ discriminates between levels of severity [13]. The Medical Psychological Questionnaire for Lung Patients (MPQL) [14] was used to assess emotional well-being (13 items) and experienced invalidity (11 items). This questionnaire uses a 3-point response scale and can be completed in 10 to 15 minutes. The MID is unknown. Functional exercise tolerance was measured with a six minute walking test [15]. This test was not encouraged, as not to interfere with self-pacing. Therefore the MID was set at 30m (as compared to the MID of 54 m for encouraged walk tests [16]).

At discharge a set of retrospective "global rating of change" questions was added. Patients were asked to rate self-perceived change on a 5-point response scale with the following range of choices: "much improved - improved - the same - worse - much worse". Self-ratings were requested for disease symptoms, exercise tolerance, disease knowledge, knowledge of correct medication use, performance of activities of daily living, performance of social activities and leisure activities.

7.3.4 Statistical analysis

Descriptive statistics (medians and interquartile ranges, missing data) were computed for the attainment scores by patients, main therapists and co-therapists. Percentages of goals attained successfully and partially successful were also computed. Differences in the level of attainment between patients and therapists was tested with the Wilcoxon matched pairs test [17].

The statistical significance of pre-post treatment change was assessed with dependent t-tests, while the clinical relevance was assessed by computing the proportion of patients
improving (P[II]) or deteriorating (P[D]), that is, with a change score above the MID [18] and by computing a variant of the effect size, the standardized response mean (SRM) [19]. The SRM is interpreted as an effect size: 0.2 represent a small relevant change, 0.5 is a moderate change and 0.8 or higher represents a large change [20].

The sensitivity to change was assessed by computing the SRM and the relative efficiency. First a mean attainment score was computed for each patient from all goals scored by that patient ('mean attainment score'). Then the SRM was computed by dividing the overall mean of the mean attainment scores by its standard deviation. The SRM of the QoLRIQ was computed by dividing the mean difference between pre- and posttest scores by the standard deviation of that difference. The SRM was preferred above the better-known effect size because attainment scores have no baseline standard deviation, which is required for the effect size.

The relative efficiency of attainment scoring in measuring change was computed with the QoLRIQ-total score as the standard. Relative efficiency was calculated as:

\[ \left( \frac{t_{\text{mean attainment score}}}{t_{\text{QoLRIQ-total score}}} \right)^2 \]

A score of more than 1.00 means the alternative method is more efficient than the standard in measuring change [21].

Reliability of attainment scoring was assessed in two ways: with the inter-rater agreement between the main therapist and the co-therapists, and with the inter-rater agreement between the patient and the main therapist. Inter-rater agreement was computed with the weighted kappa, which should be above 0.8 (range 0—1) for good reliability [17], although a lower value was expected for the patient-therapist agreement. Spearman correlation coefficients between the scores of patients, therapists and co-therapists were also computed.

The longitudinal validity of attainment scoring was assessed by correlating patient attainment scores of treatment goals with change in related external outcome measures, using Spearman correlation coefficients. First, an overall correlation was computed between the mean attainment score and the change in QoLRIQ-total score of each patient. Second, we selected the treatment goals with at least 10 scores and for which a related external outcome measure was available. Treatment goals with a similar content were grouped if that was necessary to get enough scores. The selection proceeded as follows. The treatment goal of coping with emotions was correlated with change in emotional well-being, change in experienced invalidity and change in the QoLRIQ emotions domain. Treatment goals of disease education (knowledge about medication, correct use of medication) were correlated with matching questions on self-perceived change. The combined treatment goals on social functioning were correlated with change in the QoLRIQ-domains 'general activities' and 'social activities'; and with self-perceived changes in performing leisure activities and taking on activities. Improvement of exercise tolerance was correlated with
change in distance walked during the six minute walking test and with self-perceived change in exercise tolerance. The treatment goal of improvement of functioning in activities of daily life was correlated to changes in the QoLRIQ-domains 'daily and domestic activities' and 'general activities' and to self-perceived change in performing daily activities. No external outcome measure was available for several treatment goals with 10 or more occurrences: coping with shortness of breath, improvement of self-pacing, breathing retraining, recognition of symptoms and body signals, learning the boundaries or limits of movement (preventing shortness of breath and exhaustion), balancing tension and relaxation, improving communication and/or cooperation between patient and caregivers (including correct and timely presentation of symptoms), improving communication between patient and surroundings, improvement of feeding pattern, increasing self-confidence, coping with anxiety, using a what to do'-list to prevent exacerbations when symptoms increase.

7.4 Results

General characteristics of the patients are given in table 1. The 79 patients in this study had a total of 540 individualized treatment goals, range 2 to 12 goals per patient. Altogether, 70 different treatment goals could be identified. As shown in table 2, 286 goals were scored by both the patient and the main therapist. The patient attainment score was missing for 52 goals, mostly because a descriptive evaluation was given. In comparison, 202 therapist attainment scores were missing, mostly those of pulmonologists, psychologists and nurses. The main reason given by therapists for missing scores was lack of time. The patients had a significantly higher median attainment score than the main therapist (5 versus 4, \( n = 286 \), \( p < 0.0001 \)). The median attainment scores from patient or therapist did not differ between the groups with and without external outcome measures. Most goals were successfully attained (60% with score 5 or 6) according to the patients, who were more positive than the main therapists (45%) and the co-therapists (43%). During the study, 68 patients had one or more goals related to shortness of breath (median attainment score 5); 38 patients had goals for improvement of exercise tolerance (median attainment score 5); 45 had goals for psychosocial functioning (median attainment score 5) and 36 patients had educational goals (median attainment score 5.5).
Table 7.1: general characteristics

<table>
<thead>
<tr>
<th></th>
<th>asthma</th>
<th>COPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>total patients (N)</td>
<td>20</td>
<td>59</td>
</tr>
<tr>
<td>gender (male / female)</td>
<td>5 / 15</td>
<td>25 / 34</td>
</tr>
<tr>
<td>age (years)</td>
<td>52.7 (sd 14.7)</td>
<td>62.4 (sd 8.5)</td>
</tr>
<tr>
<td>FEV₁ (L)</td>
<td>1.95 (sd 0.91)</td>
<td>0.89 (sd 0.35)</td>
</tr>
<tr>
<td>FEV₁ %predicted</td>
<td>68.2 (sd 19.8)</td>
<td>34.1 (sd 11.9)</td>
</tr>
<tr>
<td>patients with hospital admission in year pre-IPR (N and % of total patients)</td>
<td>11 (=55%)</td>
<td>24 (=41%)</td>
</tr>
<tr>
<td>days in hospital in year pre-IPR</td>
<td>37 (iqr 69)</td>
<td>33 (iqr 48)</td>
</tr>
</tbody>
</table>

Mean with standard deviation (sd) or median with interquartile range (iqr); FEV₁ = forced expiratory volume in 1 second; IPR = inpatient pulmonary rehabilitation.

Table 7.2: treatment goals and attainment scores

<table>
<thead>
<tr>
<th>assessor</th>
<th>total goals scored</th>
<th>median attainment score</th>
<th>% goals successfully attained</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>success (score 5 or 6)</td>
<td>partial (score 3 or 4)</td>
<td>no success (score 1 or 2)</td>
</tr>
<tr>
<td>patient</td>
<td>488</td>
<td>5 (iqr 1)</td>
<td>59.8</td>
</tr>
<tr>
<td>main therapist</td>
<td>286</td>
<td>4 (iqr 2)</td>
<td>44.5</td>
</tr>
<tr>
<td>co-therapist</td>
<td>58</td>
<td>4 (iqr 2)</td>
<td>43.1</td>
</tr>
</tbody>
</table>

Range of attainment scores: 1 = not at all, 6 = completely; iqr = interquartile range.

Analysis of change from pretreatment to posttreatment in external outcome measures for 42 patients showed significant improvements in all QoLRIQ-domains and emotional well-being (Table 3), but not in experienced invalidity or six minute walking distance. The mean score for emotional well-being improved from ‘unfavourable’ to ‘average’. Patients improved more than the MID of 0.5 units in all QoLRIQ-domains. Ratings for self-perceived change varied from 48% improved/much improved for doing leisure activities to 88% - 98% improved/much improved for knowledge of medication, knowledge of correct medication use and disease knowledge.
Table 7.3: pre/posttreatment change (n=42)

<table>
<thead>
<tr>
<th>domain</th>
<th>pre-treatment score (sd)</th>
<th>change score</th>
<th>p(I)</th>
<th>p(D)</th>
<th>p-value change</th>
<th>SRM</th>
</tr>
</thead>
<tbody>
<tr>
<td>QoLRIQ-total</td>
<td>4.0 (1.0)</td>
<td>0.88</td>
<td>65%</td>
<td>5%</td>
<td>&lt;0.0001</td>
<td>1.01</td>
</tr>
<tr>
<td>breathing problems</td>
<td>3.6 (1.3)</td>
<td>0.73</td>
<td>48%</td>
<td>12%</td>
<td>0.006</td>
<td>0.56</td>
</tr>
<tr>
<td>physical problems</td>
<td>3.4 (1.0)</td>
<td>0.76</td>
<td>58%</td>
<td>5%</td>
<td>0.0002</td>
<td>0.79</td>
</tr>
<tr>
<td>emotions</td>
<td>3.6 (1.4)</td>
<td>0.85</td>
<td>56%</td>
<td>3%</td>
<td>&lt;0.0001</td>
<td>0.79</td>
</tr>
<tr>
<td>general activities</td>
<td>4.4 (1.5)</td>
<td>1.51</td>
<td>80%</td>
<td>7%</td>
<td>&lt;0.001</td>
<td>0.96</td>
</tr>
<tr>
<td>triggering situations</td>
<td>3.5 (1.1)</td>
<td>0.67</td>
<td>59%</td>
<td>10%</td>
<td>0.002</td>
<td>0.75</td>
</tr>
<tr>
<td>daily activities</td>
<td>4.4 (1.3)</td>
<td>0.83</td>
<td>66%</td>
<td>11%</td>
<td>0.0006</td>
<td>0.81</td>
</tr>
<tr>
<td>social activities</td>
<td>4.4 (1.8)</td>
<td>0.67</td>
<td>56%</td>
<td>30%</td>
<td>0.04</td>
<td>0.42</td>
</tr>
<tr>
<td>MPQL-emotional well-being</td>
<td>20.1 (6.9)</td>
<td>8.0</td>
<td>-</td>
<td>-</td>
<td>&lt;0.0001</td>
<td>0.75</td>
</tr>
<tr>
<td>MPQL-experienced invalidity</td>
<td>29.5 (3.1)</td>
<td>-1.3</td>
<td>-</td>
<td>-</td>
<td>0.1</td>
<td>0.26</td>
</tr>
<tr>
<td>6-minute walking distance (m)</td>
<td>299 (124)</td>
<td>10</td>
<td>39%</td>
<td>39%</td>
<td>0.5</td>
<td>0.1</td>
</tr>
</tbody>
</table>

QoLRIQ range: 1 = not at all, 7 = very severe. MPQL: emotional well-being: higher score = better, range 13 to 39; experienced invalidity: lower score = better, range 33 to 11.
p(I), p(D): proportion of patients improving / deteriorating, i.e. change score above MID (QoLRIQ: 0.5 units; 6MWD: 30m; MPQL: unknown). SRM = standardized response mean.

Patients with a treatment goal on improvement of exercise tolerance and a 6-minute walking test before and after treatment (n=17) had a non-significant mean improvement of 6.7 m in walking distance, accompanied by significant improvements in minimal oxygen saturation during the walking test (92.8% to 94%, p=0.009), perceived exertion (4.1 to 3.1 on the modified Borg-scale, p=0.01) and perceived dyspnea (4.1 to 3.1 on the modified Borg-scale, p=0.01).

The sensitivity to change was assessed by computing the standardized response mean and the relative efficiency. The SRM of attainment scoring was 3.57, which is much higher than the already large SRM of the QoLRIQ: 1.01 (n=42). The relative efficiency of measuring change with attainment scoring versus the QoLRIQ was 10.2.

The agreement (weighted kappa) between attainment scores from the main therapist and the co-therapist was 0.33; the inter-rater agreement between patient and main therapist was 0.27. Significant correlations were found between main- and co-therapists (r=0.47, p<0.0001), patients and main therapists (r=0.42, p<0.0001) and between patients and co-therapists (r=0.49, p<0.0001).
The longitudinal validity of attainment scoring was assessed by correlating patient attainment scores with change in external outcome measures (see for all correlations table 4). The correlation between mean attainment scores and change in QoLRIQ-total score was 0.13 (n=42, p=0.44). There was a significant correlation between the treatment goal of improvement of exercise tolerance (mean attainment score 4.25; range 1 to 6) and the change in distance walked during the six minute walking test (mean change 5.9 m, range -159 to +178). The treatment goal of coping with emotions was significantly correlated with change in emotional well-being and with change in experienced invalidity, but not with change in the QoLRIQ emotions domain. The treatment goal of improvement of functioning in activities of daily life was non-significantly correlated to changes in the QoLRIQ-domains 'daily and domestic activities' and 'general activities'. Combined treatment goals on improvement of social functioning were significantly correlated to self-perceived change in taking upon activities but not to self-perceived change in leisure activities or the QoLRIQ-domains 'general activities' and 'social activities'. The treatment goals of medication knowledge and knowledge of correct use of medication were significantly correlated with their matching questions on self-perceived change.

Table 7.4: correlations of patient attainment scores of selected treatment goals with external outcome measures

<table>
<thead>
<tr>
<th>treatment goal</th>
<th>N</th>
<th>external outcome measure</th>
<th>$r_s$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping with emotions</td>
<td>12</td>
<td>MPQL-emotional well-being</td>
<td>0.64</td>
<td>0.02</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MPQL-experienced invalidity</td>
<td>0.55</td>
<td>0.07</td>
</tr>
<tr>
<td></td>
<td></td>
<td>QoLRIQ-emotions</td>
<td>0.02</td>
<td>0.9</td>
</tr>
<tr>
<td>Disease education</td>
<td>8</td>
<td>SPC disease knowledge</td>
<td>0.59</td>
<td>0.12</td>
</tr>
<tr>
<td>Correct use of medication</td>
<td>13</td>
<td>SPC correct use of medication</td>
<td>0.56</td>
<td>0.047</td>
</tr>
<tr>
<td>ADL-functioning</td>
<td>10</td>
<td>QoLRIQ-daily activities</td>
<td>0.52</td>
<td>0.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>QoLRIQ-general activities</td>
<td>0.42</td>
<td>0.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SPC performing daily activities</td>
<td>0.23</td>
<td>0.4</td>
</tr>
<tr>
<td>Social functioning</td>
<td>35</td>
<td>QoLRIQ-general activities</td>
<td>0.13</td>
<td>0.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SPC leisure activities</td>
<td>0.14</td>
<td>0.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SPC taking upon activities</td>
<td>0.47</td>
<td>0.004</td>
</tr>
<tr>
<td>Exercise tolerance</td>
<td>17</td>
<td>Six minute walking distance</td>
<td>0.50</td>
<td>0.04</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SPC exercise tolerance</td>
<td>0.14</td>
<td>0.5</td>
</tr>
</tbody>
</table>

N= number of patients with that treatment goal and a change score on external outcome measure; MPQL=medical psychological questionnaire for lung patients; QoLRIQ=quality of life for respiratory illness questionnaire; SPC = self-perceived change; $r_s$ = Spearman correlation coefficient.
The patients who participated in this study did improve after inpatient pulmonary rehabilitation according to both types of outcome measurements: standardized outcome measurement (see chapter 2 and 3) and individual attainment scoring. There was a relevant and highly significant improvement in all quality of life domains and emotional well-being. The patients gave themselves significantly higher attainment scores on their individual goals than their therapists did. Therapists and co-therapists were equally positive. The difference in attainment scores between patients and therapists point of view was expected and may be explained partly by their different points of view. Patients compare themselves to their previous situation. They see improvement with regard to prior symptoms and mostly a bad physical situation. Therapists compare the patient's improvement with the results of their clinical expertise with many patients and with the anticipated outcome. This last point leads to another, related explanation: because there is no common criterium for assessing the amount of change, attainment scores from patients, therapists and co-therapists will always differ. This is confirmed by the low values for inter-rater agreement. Formulation of the treatment goals by the whole treatment team, in consultation with the patient, did apparently not result in accordance in assessment. Possibly the goals were not formulated concrete and clear enough, both for the patient and the therapists. From a clinical viewpoint, the discrepancy between patients and therapists is useful: differing attainment scores can be used to clarify expectations and improve understanding of the treatment goal. In a similar way, low attainment scores can be used to redirect treatment towards more feasible goals.

Other psychometric characteristics were more reassuring. Subjective attainment scoring showed to be highly sensitive to change, even in comparison with the large effect size of the QoLRIQ, a disease-specific quality of life questionnaire. This finding is similar to studies with frail elderly patients that compared Goal Attainment Scaling with the Barthel Index [22-24]. The high sensitivity was expected because our method was designed to measure change.

Obviously, there were methodological problems in establishing construct validity. First, patients needed to be grouped, which contradicted the approach of individualized treatment goals. Second, it is not very logical to validate a new individualized method (attainment scoring) with the global, standardized method it should replace. Still, we found sufficient evidence for the construct validity of attainment scoring. We selected treatment goals with at least 10 occurrences and a closely related external outcome measure. These treatment goals all had moderate to high correlations with change in their related outcome measures. Because we found higher correlations with increasing specificity of the external
criterion, the validity of attainment scoring was supported. The validity of all treatment goals could not be assessed because there was no related external outcome measure for all these treatment goals or because of too few occurrences, despite the grouping of treatment goals. Several high (>0.5) but non-significant correlations in treatment goals with fewer than 10 occurrences were found (disease education, table 4; others not shown). A larger sample size and more external outcome measures are needed to establish the validity of attainment scoring clearly.

Another critique on this new assessment method is the number of missing attainment scores. Almost 10% of the patient scores and almost 40% of the main therapist scores were missing. Therapists reported a lack of time as the reason for missings. These selective missings may bias the results obtained by attainment scoring and should be minimized, partly by becoming more used to working with individually tailored goals.

A minor critique is that the new evaluation system was not investigated regarding satisfaction of the patients and the therapists with this system. Remarks by the group of patients who also experienced the previous evaluation system indicated an improved understanding of content and goals of the treatment as a whole.

Using the patient's view of outcome as a standardized method, in which the patients are asked whether they improved with regard to health related goals, was strongly advocated recently by Wright [8]. Standardized outcome assessment should be supplemented with individualized outcome assessment, especially in multi-intervention treatment programmes such as inpatient rehabilitation programmes. Questionnaires and function tests are very suitable for evaluating change in groups of patients, but they cannot be used to evaluate change in area's important to individual patients. Therefore we developed a new method of assessing outcome of inpatient pulmonary rehabilitation. Patients and therapists scored the subjective attainment level of individualized treatment goals, which were formulated by the treatment team in consultation with the patient.

Using only standardized outcome measures may result in misinterpretation of the results of individually tailored treatment programmes. This is illustrated by our finding that there was no overall improvement in the distance walked during the six minute walking test, which differs from findings of other pulmonary rehabilitation programs [1]. However, a high and significant correlation was found between the patient attainment score and the change in six minute walking distance in the group of patients who had an explicit treatment goal of improving exercise tolerance. Furthermore, these patients significantly improved in desaturation, perceived dyspnea and perceived exertion, which are also important aspects of functional exercise tolerance [25]. This implies that patients with the treatment goal of increasing exercise tolerance did improve, whereas this could not be judged from the overall group evaluation which showed a lack of change in walking distance (see chapter 2).
The deviating result in walking distance improvement may be explained both by the attention in the IPR treatment programme on self-pacing skills training and by the insufficient intensity of exercise [26]). Another explanation maintains that the 6-minute walking test may not have been the most appropriate test to measure exercise tolerance. Several patients reported in the post-treatment test that they could have walked much further than the 6 minutes of the test, indicating that a test of endurance would have been a better choice. A detailed factor analysis of walking test results is described in chapter 3 [25].

The need for assessing outcome of individualized treatment goals is confirmed by the large number of the treatment goals in this study that did not have an equivalent in the standardized outcome measures. Furthermore, the information obtained from scoring attainment of treatment goals is different from the serial assessment of change using standardized outcome measures (e.g., a quality of life questionnaire): the patients in this study improved significantly according to both the patient mean attainment scores and the change in overall quality of life, but the correlation between the two types of measurement was very low, indicating that they possibly measure different constructs. This was recently suggested also by Moser et al. [27].

Assessment of the individual patient's view of outcome has not been used previously in pulmonary rehabilitation studies, with the exception of the dyspnea-scale of the Chronic Respiratory Disease Questionnaire [28]. However, this scale asks only for physical activities in which patients are limited by their dyspnea and not for treatment goals. Recently, Moser et al. [27] used goal attainment in a study on inpatient oncological rehabilitation. These authors developed a technique of goal attainment scoring very similar to the one described in this study. Their results support the current findings, by showing a similar lack of concordance between attainment scores of patients and those of their doctors, and low to moderate correlations between attainment scores (grouped into categories of treatment goals like we did) and mean change scores on the EORTC-QLQ C30 (a quality of life questionnaire for patients with cancer).

A different result has been found in a randomized controlled trial of cardiac rehabilitation versus usual care after acute myocardial infarction [29]. In this study, patients were required to identify one activity that would reflect the patient's perception of successful recovery when attained. They found no significant difference in attainment levels between both groups, while the rehabilitation group had a significantly higher improvement in quality of life. They concluded that self-identified activity goal attainment is not useful as an outcome measure. This method differs, however, from the current method in that it uses only one goal, chosen by the patient, with a yes or no answer, instead of multiple goals based on the
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treatment and formulated by both the therapist and the patient, using a 6-point response scale.

Goal Attainment Scaling (GAS) has been used in other multiple-intervention treatments [22;24;30]. The most important steps of GAS are the construction of a treatment plan (goal attainment guide) for an individual patient, a description of the expected level of outcome and levels describing somewhat/much better/less than expected and lastly rating the performance of a patient at a predetermined time after intervention [31]. Whereas GAS seems to be reliable, valid and sensitive to change, it is time-consuming. Recently, two different standardized variant of GAS have been proposed [23;32] which seem very promising for measuring outcome on multiple individualized interventions.

We think that individualized outcome assessment is a promising method for measuring changes that are important to patients and that it can be seen as a useful complementary method for evaluating multi-intervention rehabilitation programmes. Of course, the method used in this study has some limitations. The low agreement between different assessors of outcome contains a problem. Apparently there is no satisfying agreement among therapists with each other nor with their patients. This is illustrated by the low inter-rater agreement between the main therapist and the co-therapist and the equally low agreement between the patient and the main therapist (although we did not expect a very high agreement in the latter case). We think that the major reason for the low agreement is that a precise description of the expected outcome was not included. Therefore, therapists and especially patients are assessing a goal according to their own internal standards (which may change due to treatment, a process known as response shift [33]), instead of using clearly defined outcome levels as with GAS [30]. Accounting for this internal viewing of changed goals is a new complementary method in outcome evaluation studies with chronic ill patients [33;34]. Furthermore, including a clear description of the expected outcome would be a major improvement of the current method of attainment scoring when different therapists are included as in multi-intervention rehabilitation. Specifically measuring response shift and goal shift would be another option for clarifying change in multi-intervention programmes.

Also, studies from the health psychology field have shown that patients will be more motivated to reach their health related goals when these are individually tailored. Patients tend to adopt more coping strategies to achieve their goals when these are both of importance to them and feasible [9;35]. When goals are not individually important to the patient nor sufficiently feasible, the patient most probably will disengage his behavioural efforts. This implies the importance of individual tailoring health related goals in rehabilitation programmes [36].
7.6 Conclusion

In conclusion, we presented an alternative method for assessing the individual patient's view of outcome in inpatient pulmonary rehabilitation. Patients and therapists are asked to rate the level of attainment of individually tailored treatment goals using a 6-point response scale. This method differs from standard outcome measurement in that the outcome variables are individualized which allows for the assessment of topics not addressed by standardized outcome tools. This property makes attainment scoring especially suited for evaluating rehabilitation programmes that use several interventions simultaneously. Although attainment scoring has a high sensitivity to change and a satisfying longitudinal validity, the low reliability in relation to the therapists' point of view requires more research. Including a clear description of the different levels of expected outcome, such as in GAS, would be a necessary improvement of the reported method. Supplementing traditional ways of standardized outcome measurements with individualized outcome measures seems an important new way of evaluating rehabilitation programs, especially because it acknowledges and motivates individual patients to attain their self-stated goals.
7.7 Reference List


8. Wright IG. Evaluating the outcome of treatment. Shouldn't we be asking patients if they are better? J Clin Epidemiol 2000; 53:549-553.


7.8 Appendix

Categories of individualized treatment goals in inpatient pulmonary rehabilitation

- coping with chronic shortness of breath
- coping with acute shortness of breath
- preventing shortness of breath when exercising
- improvement of self-pacing
- (early) recognition of symptoms and body signals
- recognition of symptoms and body signals when exercising
- learning the limits when exercising (preventing shortness of breath and exhaustion)
- improvement of ADL-functioning:
  - learning to move more economically (energy-saving)
  - coping with shortness of breath during selfcare
  - coping with shortness of breath during household activities
  - adapting tasks to physical ability
- breathing retraining
- decreasing cough attacks
- stop smoking and maintaining it
- education about and prevention of airway infections
- education about and avoidance of allergic triggers
- education about and avoidance of non-allergic triggers
- education on working mechanisms of medication
- education on correct use and inhalation of medication
- learning to use supplemental oxygen
- education on disease (causes, pathophysiology, treatment)
- decreasing use of escape medication
- decreasing use of oral corticosteroids
- decreasing use of psychopharmaca
- 'what to do'-list to prevent exacerbations when symptoms increase
- instruction about peakflow measurement
- improvement of exercise tolerance
- learning new sports or movement activity
- increasing muscle strength
- improvement of emotional well-being
- acceptance of impairments and handicaps
- increasing self-confidence
- coping with anxiety
- coping with emotions
- balance between tension and relaxation
- planning new daily schedules
- developing/expanding social activities and leisure activities
- increasing social skills
- learning to stand up for oneself
- weight reduction
- weight increase
- improvement of feeding pattern
- education on food and dietary schedules
- decreasing 'emotional eating'
- investigating causes of fatigue
- investigating causes of fever
- learning how to do a bronchial toilet
- help with finding regular job or study
• help with finding suitable (adapted) accommodation
• increasing outside mobility
• improving communication and/or cooperation between patient and caregivers (including correct and timely presentation of symptoms)
• improving communication between patient and surroundings
• improving speech to prevent dyspnea