



The dynamics of illness perceptions: Testing assumptions of Leventhal's common-sense model in a pulmonary rehabilitation setting

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Objectives. Although Leventhal's common-sense model (CSM) is proposed to represent a dynamic system, limited research has been conducted to investigate whether and how illness perceptions change. This study tested two hypotheses from the CSM about the dynamics of illness perceptions of patients with chronic obstructive pulmonary disease (COPD) in a pulmonary rehabilitation setting.

Design and methods. The study employed a longitudinal design. Patients with COPD ($N = 87$) who took part in a pulmonary rehabilitation programme filled out the Illness Perception Questionnaire – Revised (IPQ-R) before and after treatment and rated the degree to which the rehabilitation had led to the achievement of desired outcomes. Clinical variables and quality of life (Chronic Respiratory Disease Questionnaire) data were obtained from medical records.

Results. In line with expectations, results showed that, at baseline, longer time since diagnosis was associated to perceptions corresponding with a chronic illness model (longer illness duration, more experienced consequences, less perceived personal controllability), after correction for clinical variables. After completion of the rehabilitation programme, patients who were more convinced that their participation had led to the achievement of desired outcomes were less concerned about the negative consequences of COPD, had stronger perceptions about the

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variability in symptoms (cyclical timeline) and had stronger perceptions of personal controllability

Conclusions. We conclude that, in accordance with Leventhal *et al.*'s CSM, coping with an illness is a continuous process and the achievement of desired outcomes during treatment is likely to enable patients to adopt a more positive representation of their illness.

Within the common-sense model (CSM; Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984) representations of illness are key elements for understanding how individuals make sense of and manage threats to their health. To date, many studies have found evidence for the predictive role of patients' illness perceptions in coping responses and health outcomes (van Dijk *et al.*, 2009; Griva, Jayasena, Davenport, Harrison, & Newman, 2009; Hagger & Orbell, 2003; Scharloo *et al.*, 2007; Stockford, Turner, & Cooper, 2007).

However, to date only few studies have investigated whether and how illness perceptions evolve over time, taking into account the proposed cyclical nature of human self-regulation. Although longitudinal observational studies suggest that patients' views about their condition appear to be relatively stable (Foster *et al.*, 2008; Rutter & Rutter, 2007), two processes however have been suggested to influence the evolution of illness perceptions over time.

Firstly, when confronted with health threats, individuals initially tend to perceive their condition as acute, meaning that it has a limited duration and can be treated or cured (Leventhal *et al.*, 1984). Because of previous experience with common illnesses, and as a result of the organization of the medical care system which is primarily focused on treatment of acute conditions, individuals tend to expect illnesses to disappear by themselves or that some sort of remedy will be available. However, in case of a chronic illness, reality forces patients to abandon this 'acute' illness model to be replaced with a 'chronic' model (Leventhal *et al.*, 1984). Logically, this shift in illness models pertains to the perception of the acute versus chronic timeline of the condition. However, it can be expected that other attributes of the illness representation change as well (Leventhal *et al.*, 1997). Previous research in patients with cardiac conditions has shown that perceptions of a chronic timeline tend to increase whereas perceived controllability or curability tends to decrease over time (Leventhal *et al.*, 1980; Petrie & Weinman, 1997; Sheldrick, Tarrier, Berry, & Kinsey, 2006). In patients with diabetes, Lawson and colleagues have shown that emotional representations decrease within 2 years after the diagnosis whereas illness coherence increases (Lawson, Bundy, & Harvey, 2008). In a 6-year longitudinal study of patients with osteoarthritis, Bijsterbosch and colleagues found that whereas the dimensions chronic timeline and illness coherence had increased, patients reported a reduced perception of personal control over their illness and emotional reaction to their disease (Bijsterbosch *et al.*, 2009). Taken together, these data suggest that in chronic illnesses, perceptions of a chronic timeline and illness coherence increase, whereas perceived controllability and emotional representations decrease over time.

Secondly, within the CSM it is assumed that 'representations are shaped and reshaped by the success or failure of specific coping procedures for preventing, moderating and curing disease processes' (Leventhal, Brissette, & Leventhal, 2003). In this light, following treatment can be regarded as a specific way of coping with an illness (Horne & Weinman, 1998). As new information from the appraisal stage is

incorporated in the initial representation of the health condition (Leventhal *et al.*, 1984), the individual's post-treatment illness representations are likely to be influenced by the appraisal of the outcomes of treatment. It can therefore be expected that a positive appraisal of the outcomes of treatment is associated with more optimistic representations of the illness. Support for this idea has been provided by Foster and colleagues in a study of nearly 1,600 patients with back pain (Foster *et al.*, 2008). In the whole group, patients' illness perceptions had remained stable over the course of six months. However, those patients who reported benefit from treatment showed a greater reduction in consequences, number of symptoms associated with their condition and emotional representations compared with patients who reported a poor treatment outcome. Additionally, patients with a good outcome had stronger perceptions of personal and treatment control and illness coherence.

The purpose of this study was to investigate both proposed mechanisms related to the evolution of illness perceptions among patients with chronic obstructive pulmonary disease (COPD) who were referred to a pulmonary rehabilitation centre. COPD is a progressive condition, characterized by expiratory airflow limitation which cannot be fully reversed by medication. Common are symptoms of dyspnoea, fatigue, productive cough, and a range of systemic consequences such as muscle dysfunction, chronic inflammation, and nutritional abnormalities. Pulmonary rehabilitation is an effective non-pharmacological treatment option for patients with COPD who suffer from disability and/or poor disease management despite otherwise optimal medical treatment. Mutual goal setting between the patient and professional, and monitoring of goal progress are integrated elements of pulmonary rehabilitation programmes (Ries *et al.*, 2007).

Investigating illness perceptions in this group of patients allows us to test the following two hypotheses: (1) patients' illness perceptions at baseline are expected to be related to time since diagnosis. It would be expected that longer time since diagnosis will be associated with stronger perceptions about the chronic nature of their illness. Additionally, based on results from other studies in chronic illnesses we expect that longer time since diagnosis will be positively associated with illness coherence and negatively related to confidence that the illness can be controlled (personal and treatment controllability) and emotional reactions to the illness. Finally, in line with the slowly progressive character of COPD, we expect patients to experience greater consequences of their disease with increasing time since diagnosis. (2) In accordance with the proposed cyclical nature of self-regulation, we expect that patients' rating of the degree to which they have been able to achieve personal relevant treatment objectives in the rehabilitation will be related to post-treatment illness representations. In line with findings by Foster *et al.* (2008), it is expected that a positive evaluation of the outcomes of rehabilitation is associated with more optimistic post-treatment illness representations, i.e., less negative consequences, less intense emotional responses to COPD, and increased perceived controllability of the illness. We especially expect this association to be true for patients' perception of personal controllability, as achieving one's goals and the related sense of accomplishment have shown to be important factors in the perception of personal control (Bandura, 1997; Brock *et al.*, 2009; Scherer, Schmieder, & Shimmel, 1998). No association is expected between the appraisal of treatment outcomes and post-treatment timeline perceptions, coherence, and symptoms associated with the illness (illness identity).

Methods

Participants

Between November 2005 and November 2007, consecutive patients diagnosed with COPD who had been referred to a centre for pulmonary rehabilitation (Rehabilitation Centre Breda, Sint Franciscus Gasthuis Rotterdam (SFG), Rijnland Rehabilitation Centre Leiden) were invited to participate in this study. Participating patients received a questionnaire and were requested to return it before the start of the rehabilitation. Patients gave written informed consent to participate in the study, which included permission to obtain information from their medical files. Patients who had already started rehabilitation or who had primary lung conditions other than COPD were excluded from the study. The study was approved by the Leiden University Medical Center (LUMC) and SFG ethics committees and subsequently by the boards of the rehabilitation centres. After completion of the rehabilitation programme patients were contacted and invited to fill out a follow-up questionnaire. Of the 108 eligible patients who had completed the rehabilitation programme, 10 (9%) could not be contacted at follow-up and 7 (6%) refused to fill out a second questionnaire, leaving 91 questionnaires that were sent by mail, of which 87 (96%) were returned. No differences in baseline illness perceptions, demographics, lung function, walk test result, and body mass index (BMI) were found between patients who returned both questionnaires and those who dropped out of the study.

Rehabilitation programme

The 12-week rehabilitation programme consisted of supervised exercises (strength and endurance training, activities of daily living training), relaxation training, breathing exercises, and group education. Additional counselling was tailored to the patient's individual needs and included support by a psychologist or social worker, nutritional interventions, occupational therapy, and smoking cessation counselling. All rehabilitation centres offered an out-patient programme (3 days a week). In Breda, an intensive programme of (5 days a week) was also available. During the intake phase, practitioners, and patients identified the objectives for the pulmonary rehabilitation programme. Goal progression was monitored on a regular basis (often weekly). After completion of the 12-week programme, all three centres reviewed the outcomes of treatment together with their patients.

Baseline assessment

Participants were asked to fill out a questionnaire which included socio-demographic questions (age, sex, education, marital status, year of diagnosis, smoking status, and pack years) and the Illness Perception Questionnaire - Revised (IPQ-R; Moss-Morris *et al.*, 2002). The IPQ-R is a validated and reliable instrument used to assess representations of illness among diverse patient groups, including patients with COPD (Howard, Hallas, Wray, & Carby, 2009; Kaptein *et al.*, 2008).

During the assessment phase in the rehabilitation centre, baseline pulmonary function tests included post-bronchodilator expiratory flow rates (FEV₁ and percentage of predicted value of FEV₁ (FEV₁%pred)), and vital capacity (VC and VC%pred). A classification of disease severity (GOLD stage) was made according to international guidelines (Rabe, Beghe, Luppi, & Fabbri, 2007). A field exercise test was performed by means of the 6-min walk test (Palange *et al.*, 2007). Dyspnoea and perceived exertion (Borg CR10) were assessed after the walk test (Borg, 1982). Patients' weight, BMI, and

fat-free mass index were recorded, giving an indication of the systemic effects of the disease. Quality of life was assessed with the Chronic Respiratory Questionnaire (CRQ) (Guyatt, Berman, Townsend, Pugsley, & Chambers, 1987). The CRQ is a widely used interviewer-administered quality of life instrument in pulmonary research and covers four domains: dyspnoea (five items), fatigue (four items), emotional functioning (seven items), and mastery (four items). All questions are answered on a seven-point scale, with higher scores reflecting better functioning.

Follow-up assessment

At the end of the rehabilitation programme, the walk test, BMI, and CRQ were repeated. As pulmonary rehabilitation is assumed to improve patients' functional status without affecting lung function (Casaburi & Zuwallack, 2009), forced expiratory volume (FEV₁%pred) was assessed only at baseline. Within one month of completing the rehabilitation programme, patients received a second questionnaire. This questionnaire included the IPQ-R and questions about the evaluation of the programme. Treatment goal achievement was assessed by asking patients to rate (1–10 scale) the degree to which they felt they had been able to achieve their overall treatment objectives by participating in the rehabilitation programme.

Statistical analyses

Descriptive analyses were used to investigate frequencies and distribution of patients' socio-demographic and medical characteristics and illness perceptions. Inspection of the variable time since diagnosis showed that four patients had been diagnosed more than 25 years ago. These patients were classified as outliers and were excluded from the subsequent analyses. Associations between time since diagnosis and illness perceptions at baseline were performed by means of Pearson correlation analyses. Multivariate analyses of covariance were used to test the association of time since diagnosis (two groups, based on median split) and prior participation in rehabilitation with baseline illness perceptions. Clinical variables included in the analysis as covariates were airway obstruction (percentage of predicted forced expiratory volume in 1 s, FEV₁%pred), exercise tolerance (6-min walk distance, 6MWD), and BMI. These variables are frequently used parameters of disease severity in pulmonary research (Cote & Celli, 2005; Watz, Waschki, Meyer, & Magnussen, 2009).

Paired samples *t* tests were used to investigate whether post-treatment clinical variables and illness perceptions differed from baseline levels. Pearson correlation analyses were performed to examine the association between changes in illness perceptions and changes in 6MWD and BMI. Hierarchical regression analyses were used to explain variance in post-treatment illness perceptions. Baseline perceptions, time since diagnosis, and perceived achievement of treatment objectives were entered as independent variables in three separate steps, using the forced entry method. All analyses were performed using the Statistical Package for the Social Sciences (SPSS version 14.0).

Results

Patient characteristics

Characteristics of patients at baseline are presented in Table 1. Most patients were living with a partner and were retired (mean age 63 years). Most patients indicated having quit

Table 1. Patient baseline characteristics

	Mean (SD)	N (%)
Age (mean, SD)	63.3 (9.0)	
Years since diagnosis	6.5 (6.4)	
Sex		
Female		37 (43)
Male		50 (57)
Relational status		
Partner		64 (74)
Single		22 (26)
Working status		
Active		17 (20)
Retired		69 (80)
Smoking status		
Never smoker		6 (7)
Stopped smoking		70 (81)
Infrequent smoker		3 (4)
Daily smoker		7 (8)
Diagnosis		
COPD		83 (96)
COPD + Asthma		3 (4)
GOLD stage		
I		8 (9)
II		26 (30)
III		35 (40)
IV		18 (21)
FEV ₁ (litres)	1.3 (0.6)	
FEV ₁ %pred	47 (20)	
SaO ₂ rest %	94.7 (2.4)	
6MWD (metres)	381 (117)	
Borg fatigue post 6MWD	4.5 (2.3)	
Borg dyspnoea post 6MWD	5.0 (2.2)	
Body mass index (kg/m ²)	27.4 (5.7)	
Fat-free mass index (kg/m ²)	17.2 (3.1)	
CRQ dyspnoea	16.1 (4.9)	
CRQ fatigue	15.0 (4.5)	
CRQ emotional functioning	32.2 (7.9)	
CRQ mastery	19.1 (5.2)	

Note. FEV₁, forced expiratory volume in 1 s; FEV₁%pred, percentage of predicted FEV₁; SaO₂ rest %, oxygen saturation at rest; 6MWD, 6-min walk distance; CRQ, Chronic Respiratory Questionnaire.

smoking before the start of the rehabilitation programme. Sixty-one per cent of the patients had severe to very severe COPD (GOLD-stage III/IV, i.e., less than 50% of predicted value of forced expiratory volume in 1 s).

Illness perceptions at baseline

All subscales of the IPQ-R showed moderate to good internal consistency. Patients considered treatment for COPD to be effective in controlling symptoms, but not in curing the disease (the average score of the IPQ-R treatment curability item was lower

than the other items in the treatment control subscale (planned contrast $F(1, 84) = 303.7, p < .001$). To distinguish treatment controllability from treatment curability, the item about curability was removed from the IPQ-R treatment control subscale.

Correlations analyses indicated that time since diagnosis was associated with greater perceived consequences ($r = .31, p = .007$) and stronger chronic timeline perceptions ($r = .33, p = .003$; see Table 2). Perceptions of personal control were inversely related to time since diagnosis ($r = -.40, p < .001$). There was a negative relationship between time since diagnosis and the perception of treatment controllability, although the strength of this correlation did not reach significance ($p = .098$). The expected associations of time since diagnosis with illness coherence and emotional representations were not confirmed.

Overall, the illness perceptions of patients who had been diagnosed 5 years or more ago ($N = 43$) differed from perceptions of patients who had been diagnosed within the past 4 years ($N = 37$) after controlling for differences in clinical variables (MANCOVA $F(8, 68) = 4.10, p < .001$). Univariate tests indicated that patients who were diagnosed 5 years or more ago attributed more symptoms to their COPD, experienced greater consequences from their disease, and had stronger perceptions about the chronicity of their illness (see Table 3). Additionally, patients who were diagnosed 5 years or more ago held less optimistic perceptions of personal controllability than patients who had been diagnosed more recently. Clinical parameters forced expiratory volume in 1 s ($FEV_1\%$ pred), 6MWD, and BMI that were included as covariates were not significantly related to baseline illness perceptions (see also Table 2).

Patients who were referred to a rehabilitation programme for the first time ($N = 53$) and those who had participated in a rehabilitation programme before ($N = 27$) held comparable perceptions of their illness, after correcting for differences in clinical variables (MANCOVA $F(8, 68) = 1.05, p = .41$).

Outcomes of pulmonary rehabilitation

Paired samples t tests showed that rehabilitation was effective in increasing patients' walk distance from 381 to 415 m ($t(72) = -3.61, p = .001$), while decreasing Borg dyspnoea scores after the walk test from 5.1 to 4.6 ($t(68) = 1.99, p = .05$). Post-treatment Borg fatigue scores however, were not significantly lower than at baseline. Patients' BMI had remained unchanged at 27.5 kg/m².

Perceived accomplishment of treatment objectives

Most patients indicated that the rehabilitation had been successful with only 14% of patients rating the degree to which their participation in rehabilitation had led to desired outcomes with a mark 5 or lower on a 10-point scale ($M = 7.5, SD = 1.7$). Perceived goal accomplishment was related to an increase in 6MWD ($r = .30, p = .027$) and a decrease in Borg dyspnoea scores after the walk test ($r = -.39, p = .004$). Goal accomplishment was also related to a decrease in Borg fatigue scores, although this association did not reach statistical significance ($r = -.22, p = .12$). Perceived goal accomplishment was unrelated to change in weight or BMI. Patients' evaluation of treatment goal achievement was correlated with an increase in perceived quality of life (CRQ change scores from baseline) for the domains of dyspnoea ($r = .41, p = .002$),

Table 2. Associations between illness perceptions and illness characteristics at baseline

	1	2	3	4	5	6	7	8	9	10	11	12
1. Identity	1	.41***	.19	.20	-.04	.04	-.21*	.28**	.17	-.03	.02	-.19
2. Consequences		1	.33**	-.03	.00	-.16	-.08	.45***	.31**	-.28*	-.15	-.16
3. Timeline chronic			1	.09	-.04	-.21	.17	.05	.33**	-.11	.03	-.07
4. Timeline cyclical				1	.20	-.11	-.43***	.29**	-.12	.10	.03	.10
5. Personal control					1	.34**	.02	.20	-.40***	-.05	-.16	.30*
6. Treatment control						1	.22*	-.12	-.19	-.09	.04	.11
7. Illness coherence							1	-.46***	.02	-.17	-.14	.15
8. Emotional representation								1	-.14	-.02	-.01	-.11
9. Time since diagnosis									1	-.19	.06	-.21
10. FEV ₁ %pred										1	.30**	.31**
11. Body mass index											1	-.03
12. 6MWD												1

Note. FEV₁%pred, percentage of predicted forced expiratory volume in 1 s; 6MWD, 6-min walk distance; * $p < .05$; ** $p < .01$; *** $p < .001$.

Table 3. Illness perceptions at baseline of patients diagnosed less than 5 years ago ($N = 37$) and patients diagnosed 5 or more years ago ($N = 43$)

Illness perceptions	Range	Cronbach's alpha	< 5 years mean (SD)	≥ 5 years mean (SD)	Univariate F df (1, 75)	p
Identity	0–15	–	4.8 (2.0)	5.8 (2.4)	4.84	.03
Consequences	6–30	.65	19.5 (4.1)	21.6 (3.3)	5.15	.03
Timeline chronic	6–30	.81	24.8 (3.9)	28.2 (2.5)	20.79	< .001
Timeline cyclical	4–20	.73	13.3 (3.1)	12.9 (3.7)	0.00	.95
Personal control	6–30	.67	20.4 (3.2)	18.3 (4.1)	5.63	.02
Treatment control	4–20	.72	14.4 (2.5)	13.7 (2.4)	1.50	.22
Illness coherence	5–25	.81	18.0 (3.2)	17.9 (4.1)	0.02	.87
Emotional representation	5–25	.90	14.9 (5.0)	14.5 (4.7)	0.34	.56

fatigue ($r = .53$, $p < .001$), and mastery ($r = .34$, $p = .014$) but not for the domain emotional functioning ($r = .20$, $p = .151$).

Changes in illness perceptions

Paired samples t tests showed that, at a group level, scores on most of the eight IPQ-R subscales had remained unchanged. However, the average scores of the cyclical timeline and personal control subscales were higher after treatment than at baseline (Table 4). Changes in illness perceptions were comparable in the three rehabilitation centres.

Table 4. Illness perceptions (IPQ-R) of patients with COPD at baseline (T1) and after pulmonary rehabilitation (T2)

Illness perceptions	T1 mean (SD)	T2 mean (SD)	T2 – T1
Identity	5.3 (2.2)	5.4 (2.7)	+0.1
Consequences	20.6 (4.0)	20.4 (3.8)	–0.2
Timeline chronic	26.6 (3.6)	27.1 (3.4)	+0.5
Timeline cyclical	13.0 (3.3)	13.8 (2.8)	+0.8*
Personal control	19.2 (3.8)	20.3 (3.5)	+1.1**
Treatment control	13.9 (2.7)	14.0 (2.4)	+0.1
Illness coherence	18.0 (3.6)	18.4 (3.5)	+0.4
Emotional representation	14.5 (4.8)	14.0 (4.8)	–0.5

* $p < .05$; ** $p < .01$.

Changes in illness perceptions occurred in a coherent manner (see Table 5). Patients who had adopted a more optimistic view about the consequences of their disease, also attributed less symptoms to their disease, had a less intense emotional response to their illness and were more convinced that their illness had a cyclical nature. Furthermore, patients with increased perceptions of personal controllability had also gained confidence in the effectiveness of treatment. Finally, increased understanding of the condition was related to a decrease in emotional representations.

An improvement in walk distance was related to a reduction in perceived consequences ($r = -.29$, $p = .02$) and emotional representations ($r = -.25$, $p = .04$) but not to the other six subscales of the IPQ-R. A change in weight or BMI was not related to a change in any of the illness perceptions dimensions.

Table 5. Associations between IPQ-R change scores

	1	2	3	4	5	6	7	8
1. Identity	1	.25*	.05	-.08	-.17	-.06	-.13	.19
2. Consequences		1	-.09	-.39***	.02	-.15	-.10	.22*
3. Timeline chronic			1	-.02	.14	-.19	.09	-.03
4. Timeline cyclical				1	.14	.01	-.00	-.14
5. Personal control					1	.38***	.23*	-.02
6. Treatment control						1	.13	-.00
7. Illness coherence							1	-.31**
8. Emotional representation								1

* $p < .05$; ** $p < .01$; *** $p < .001$.

Post-treatment illness perceptions

Patients' post-rehabilitation IPQ-R subscale scores were significantly correlated with IPQ-R values at baseline (correlations varied between $r = .39$ (treatment control) and $r = .68$ (emotional representations), data not shown). Accordingly, results from hierarchical regression analyses indicated that pre-treatment illness perceptions were important predictors of post-treatment illness perceptions (Table 6). Time since diagnosis (added as a covariate in step 2) added to the explanation of variance in

Table 6. Hierarchical regression analyses predicting post-rehabilitation (T2) illness perceptions

Illness perceptions T2	Step	Independent variables	ΔR^2 (%)	Adj. R^2 (%)	ΔF	β
Identity	1	Identity T1	30	28	23.06***	0.52***
	2	Years since diagnosis	2	28	1.18	0.12
	3	Goal achievement	1	28	0.89	-0.11
Consequences	1	Consequences T1	37	36	36.35***	0.58***
	2	Years since diagnosis	0	35	0.00	-0.01
	3	Goal achievement	7	40	5.81*	-0.26**
Timeline chronic	1	Timeline chronic T1	33	31	25.27***	0.66***
	2	Years since diagnosis	5	35	3.88†	-0.24†
	3	Goal achievement	0	34	0.14	-0.04
Timeline cyclical	1	Timeline cyclical T1	26	24	18.24***	0.46***
	2	Years since diagnosis	0	23	0.00	0.02
	3	Goal achievement	7	29	5.38*	0.27*
Personal control	1	Personal control T1	26	25	18.11***	0.28***
	2	Years since diagnosis	9	33	7.23*	-0.35**
	3	Goal achievement	9	41	7.66**	0.31**
Treatment control	1	Treatment control T1	25	23	18.14***	0.50***
	2	Years since diagnosis	0	22	0.00	0.03
	3	Goal achievement	3	24	2.00	0.17
Illness coherence	1	Illness coherence T1	17	17	10.90***	0.41***
	2	Years since diagnosis	0	17	0.13	0.05
	3	Goal achievement	0	17	0.19	0.06
Emotional representation	1	Em. representation T1	44	43	42.73***	0.65***
	2	Years since diagnosis	0	42	0.42	-0.08
	3	Goal achievement	2	43	1.67	-0.13

† $p < .07$; * $p < .05$; ** $p < .01$; *** $p < .001$.

post-treatment illness perceptions with regard to the IPQ-R timeline chronic and personal controllability subscales. The perception of the chronic nature of COPD and patients' sense of control over the illness and symptoms increased to a greater extent for patients who had been diagnosed more recently. The degree to which patients felt they had been able to achieve relevant outcomes (step 3) was related to three of the IPQ-R subscales (consequences, timeline cyclical, and personal control). The more patients felt they had achieved their treatment objectives, the less serious they perceived the consequences of having COPD. Furthermore, achievement of treatment objectives was associated with stronger perceptions of COPD having a cyclical nature, and a greater confidence in one's ability to control the symptoms.

Discussion

In support of Leventhal's CSM, illness perceptions of patients with COPD have previously shown to be associated with coping, self-management, and well-being (Kaptein *et al.*, 2008). Illness perceptions of patients with COPD have also been found to be related to attendance at pulmonary rehabilitation (Fischer *et al.*, 2009). Although these studies lend support to the role of illness perceptions in self-regulation, these studies have not taken into account the possible variability of patients' perceptions over time. The current study is the first to investigate two assumptions within Leventhal's CSM about the evolution of illness representations among patients with COPD who participate in a pulmonary rehabilitation programme. The first hypothesis was that, in chronic illness, patients' representations shift from an initial 'acute' illness schema to a 'chronic' model. Confirming previous studies with different patient populations (patients with cardiac conditions, diabetes, and osteoarthritis) and time intervals, our data showed that patients' perceptions of the chronic timeline and perceived consequences had increased with time since diagnosis, whereas perceived controllability had decreased. One might expect that over time, patients learn to cope more effectively with their illness and hence experience more personal control over their condition. However, COPD is a slowly progressing disease that causes the degree of airflow obstruction to increase steadily over the years. Disease progression is usually associated with more intense symptoms and disability and therefore it becomes more and more difficult to perform daily activities. A follow-up analysis supported this idea by showing that patients diagnosed 5 years or more ago experienced more symptoms than those diagnosed more recently (IPQ-R symptoms subscale score 8.2 vs. 6.5, respectively, $t(85) = -2.82, p = .006$). In addition, with increasing illness severity patients usually experience more frequent and more intense periods of exacerbations (de Oca *et al.*, 2009; Franciosi *et al.*, 2006). These periods of temporary aggravations in symptoms are often difficult to predict and to control. This may cause patients to gradually lose confidence in their ability to control the illness and its symptoms. The influence of exacerbations frequency and severity on patients' illness perceptions is an important topic for further research.

Our second hypothesis was that a positive appraisal of the outcomes of rehabilitation would be related to more optimistic post-treatment illness perceptions, especially personal control. Our results supported this assumption by demonstrating that the degree to which patients considered their participation in a rehabilitation programme to have led to the achievement of desired outcomes, was related to perceived controllability of the illness. Additionally, perceptions of negative consequences of

COPD and cyclical timeline were more optimistic in those patients who had a positive appraisal of the outcomes of rehabilitation.

Because we expected that a change in illness representations would be the result of the individual's appraisal rather than the effect of treatment *per se*, we had not formulated a specific hypothesis about the overall effect of the rehabilitation programme on patients' representations. Nonetheless, our data indicated that scores on two of the eight subscales of the IPQ-R had increased after the programme. Firstly, cyclical timeline perceptions grew stronger during the rehabilitation programme, which, at first sight, might seem somewhat surprising considering the chronic character of COPD. However, perceptions of a chronic and a cyclical timeline should be considered as separate cognitions since the association between both perceptions was negligible (see Table 2). Patients' experiences with episodes of exacerbations may also provide an explanation for the increase in cyclical timeline. According to the CSM, personal experience with the illness and social communication are important sources of information for illness representations (Leventhal *et al.*, 1984). Therefore, both the occurrence of an exacerbation (either a personal experience or witnessing fellow patients suffering from exacerbations) and education about exacerbations, provided during the rehabilitation programme, emphasize the cyclical nature of the symptoms in COPD. Additional support for the 'exacerbation hypothesis' was provided by a follow-up analysis which showed that change among the items that make up the IPQ-R cyclical timeline subscale was demonstrated most clearly within the item 'I go through cycles in which my illness gets better and worse'. An alternative explanation for the increase in timeline cyclical scores is that patients will have paid more attention to the variations in their symptoms during the rehabilitation course. This focus on bodily sensations is particularly emphasized during the breathing and relaxation exercises, which may have made patients more aware of the natural variation in their sensations. Finally, increased perceptions of the cyclical nature of COPD may reflect patients adopting a more positive outlook, as patients may be convinced that, although their illness will last for the rest of their lives, there will be periods in which they will experience fewer, or less intense consequences from their disease. Support for this hypothesis can be found in Table 5. If this is the case, then there is also a downside to this more optimistic outlook, as a recent study showed that perceptions of a cyclical timeline may be associated with less adherent medication taking in asthma patients (Halm, Mora, & Leventhal, 2006). Future research is needed to investigate how these changes in perceptions are related to self-management behaviour after pulmonary rehabilitation.

Secondly, at a group level our results demonstrated an increase in perceived personal control after the rehabilitation programme. This result is in line with results from a study by Arnold and colleagues demonstrating that multidisciplinary pulmonary rehabilitation programmes (including supervised exercise, pharmacological, nutritional, and psychosocial interventions) can lead to an increase in patients' self-efficacy in controlling symptoms (Arnold *et al.*, 2006). This finding is encouraging since perceptions of personal controllability have consistently been found to be associated with adaptive coping patterns, such as problem-focused coping and positive reappraisal (Hagger & Orbell, 2003), and better self-management routines (Dowson, Mulder, Town, & Frampton, 2004). Additionally, improvements in personal control after a reactivation/rehabilitation programme have been found to be related to reductions in anxiety, depression, and fatigue (Michie, O'Connor, Bath, Giles, & Earll, 2005; Moss-Morris, Sharon, Tobin, & Baldi, 2005).

Baseline illness perceptions of patients who had participated in rehabilitation before were comparable to those who had been referred for a first time. This might seem surprising, given the beneficial effect of pulmonary rehabilitation on patients' perceptions, as described above. However, a follow-up analysis revealed that patients who had participated in rehabilitation before had a longer history of COPD, compared with patients who had never participated in rehabilitation (10 vs. 5 years, respectively, $t(73) = -2.93$, $p = .004$). As our data show that longer time since diagnosis is associated with more negative perceptions, it is possible that the positive influence of previous PR participation on patients' perceptions was negated by the longer illness history.

This study investigated the contribution of patients' appraisals of participating in a rehabilitation programme to changes in their illness representations. One limitation to this study is the use of a single item subjective evaluation of rehabilitation outcome, which rules out the possibility of establishing the internal consistency. Nevertheless, this simple evaluation of the perceived outcomes of the rehabilitation programme was significantly associated with an improvement in subjective and objective measures of health status (decrease in fatigue and dyspnoea and improvement in walk distance). Furthermore, it was deemed appropriate to use a patient evaluation rather than a rating of treatment goal achievement judged by a therapist, as ratings of patients and professionals tend to differ (van Stel, Colland, Heins, Rijssenbeek-Nouwens, & Everaerd, 2002). Our results indicate that successful participation in rehabilitation is associated with more optimistic post-treatment illness perceptions. However, future research needs to investigate which specific goals are related to change in illness representations.

Another limitation to this study is the use of the standard IPQ-R subscale for treatment controllability since this combines the concepts of controllability and curability. Our data showed that these beliefs reflect two different phenomena and hence should be separated. As we omitted the item about curability from the subscale, this reduces the mean score of the scale, which makes it difficult to compare our data with other studies. Furthermore, the formulation of the questions referring to treatment control does not refer to a specific treatment. Although patients were invited to take part in a study 'about patients' ideas with regard to COPD and pulmonary rehabilitation', we cannot be certain whether patients were referring to pulmonary rehabilitation or to treatment in general.

Notwithstanding these limitations, we feel that results from this study have some practical implications for managing patients' expectations as well as during the intake phase goal-setting. Promoting patients' motivation throughout the programme requires patients to expect they can achieve personally relevant outcomes. Previous research showed that when expectations are too high, disappointment may follow with detrimental consequences for patients' sense of control and motivation to continue their efforts (Jones, Harris, Waller, & Coggins, 2005; Rothman, 2000; Sears & Stanton, 2001). A conservative goal-setting strategy at the start of the programme and setting a new goal once the objective has been accomplished is therefore probably more beneficial for patients' morale and their illness perceptions than having to lower one's expectations during the course of the programme.

A second implication pertains to the timing of rehabilitation in the disease process. Pulmonary rehabilitation is usually offered to patients who suffer from disability or are unable to adjust to their illness, despite otherwise optimal medical care (Nici *et al.*, 2006). Many of the study patients have had considerable experience in living with their

chronic condition and will have developed their personal techniques to manage the illness. Results from this study showed that longer time since diagnosis was associated with lower perceptions of treatment efficacy and personal control, which might have a negative influence on patients' motivation to comply with the treatment regimen (Fischer *et al.*, 2009). In addition, results from our analyses showed that, if one accounts for differences in baseline perceptions, longer time since diagnosis was related to lower post-treatment perceptions of personal control over the illness. Intervention studies that have specifically targeted patients' illness representations (which was not the primary focus of our rehabilitation programme) have shown to be more effective when delivered shortly after the onset of the illness or in times of an acute health threat, (Petrie, Buick, Weinman, Cameron, & Ellis, 2002; Skinner *et al.*, 2006) compared to when patients are in a stable condition (Goodman, Morrissey, Graham, & Bossingham, 2005; Theunissen, de Ridder, Bensing, & Rutten, 2003). Future studies can shed light on whether pulmonary rehabilitation programmes, offered earlier in the disease process or immediately after an exacerbation, produce better results with regard to improving patients' perceived personal control and self-management behaviour after rehabilitation.

In summary, this study lends support to the dynamic character of illness perceptions. Whereas patients' perceptions about the seriousness and controllability of their illness tend to become less optimistic over time, treatment that is perceived as successful can have a positive effect on patients' perception of illness consequences and controllability. Therefore, future studies that investigate the effect of treatment on patients' illness perceptions need to take into account the individual's appraisal of the outcomes of treatment.

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References

- Arnold, R., de Jongste, M. J. L., Otten, V., Koëter, G. H., Wempe, J. B., Ranchor, A. V., ... Sanderman, R. (2006). Changes in personal control as a predictor of quality of life after pulmonary rehabilitation. *Patient Education and Counseling*, *61*, 99–108. doi:10.1016/j.pec.2005.02.015
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W. H. Freeman.
- Bijsterbosch, J., Scharloo, M., Visser, A. W., Watt, I., Meulenbelt, I., Huizinga, T. W. J., ... Kloppenburg, M. (2009). Illness perceptions in patients with osteoarthritis: Change over time and association with disability. *Arthritis and Rheumatism*, *61*, 1054–1061. doi:10.1002/art.24674
- Borg, G. A. V. (1982). Psychophysical bases of physical exertion. *Medicine and Science in Sports and Exercise*, *14*, 377–381.
- Brock, K., Black, S., Cotton, S., Kennedy, G., Wilson, S., & Sutton, E. (2009). Goal achievement in the six months after inpatient rehabilitation for stroke. *Disability and Rehabilitation*, *31*, 880–886. doi:10.1080/09638280802356179
- Casaburi, R., & Zuwallack, R. (2009). Pulmonary rehabilitation for management of chronic obstructive pulmonary disease. *New England Journal of Medicine*, *360*, 1329–1335. doi:10.1056/NEJMct0804632

- Cote, C. G., & Celli, B. R. (2005). Pulmonary rehabilitation and the BODE index in COPD. *European Respiratory Journal*, *26*, 630–636. doi:10.1183/09031936.05.00045505
- de Oca, M. M., Tálamo, C., Halbert, R. J., Perez-Padilla, R., Lopez, M. V., Muiño, A., ... Menezes, A. M. B. (2009). Frequency of self-reported COPD exacerbation and airflow obstruction in five Latin American cities. *Chest*, *136*, 71–78. doi:10.1378/chest.08-2081
- Dowson, C. A., Mulder, R. T., Town, G. I., & Frampton, C. (2004). Psychopathology and illness beliefs influence COPD self-management. *Journal of Psychosomatic Research*, *56*, 333–340. doi:10.1016/S0022-3999(03)00040-0
- Fischer, M. J., Scharloo, M., Abbink, J. J., van't Hul, A. J., van Ranst, D., Rudolphus, A., ... Kaptein, A. A. (2009). Drop-out and attendance in pulmonary rehabilitation: The role of clinical and psychosocial variables. *Respiratory Medicine*, *103*, 1564–1571. doi:10.1016/j.rmed.2008.11.020
- Foster, N. E., Bishop, A., Thomas, E., Main, C., Horne, R., Weinman, J., & Hay, E. (2008). Illness perceptions of low back pain patients in primary care: What are they, do they change and are they associated with outcome? *Pain*, *136*, 177–187. doi:10.1016/j.pain.2007.12.007
- Franciosi, L., Page, C., Celli, B., Cazzola, M., Walker, M., Danhof, M., ... Della Pasqua, O. E. (2006). Markers of exacerbation severity in chronic obstructive pulmonary disease. *Respiratory Research*, *7*, 74. doi:10.1186/1465-9921-7-74
- Goodman, D., Morrissey, S., Graham, D., & Bossingham, D. (2005). The application of cognitive-behaviour therapy in altering illness representations of systemic lupus erythematosus. *Behaviour Change*, *22*, 156–171. doi:10.1375/bech.2005.22.3.156
- Griva, K., Jayasena, D., Davenport, A., Harrison, M., & Newman, S. P. (2009). Illness and treatment cognitions and health related quality of life in end stage renal disease. *British Journal of Health Psychology*, *14*, 17–34. doi:10.1348/135910708X292355
- Guyatt, G. H., Berman, L. B., Townsend, M., Pugsley, S. O., & Chambers, L. W. (1987). A measure of quality of life for clinical trials in chronic lung disease. *Thorax*, *42*, 773–778. doi:10.1136/thx.42.10.773
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, *18*, 141–184. doi:10.1080/088704403100081321
- Halm, E. A., Mora, P., & Leventhal, H. (2006). No symptoms, no asthma: The acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma. *Chest*, *129*, 573–580. doi:10.1378/chest.129.3.573
- Horne, R., & Weinman, J. (1998). Predicting treatment adherence: An overview of theoretical models. In L. Myers & K. Midence (Eds.), *Adherence to treatment in medical conditions* (pp. 25–50). Amsterdam: Harwood Academic Publishers.
- Howard, C., Hallas, C. N., Wray, J., & Carby, M. (2009). The relationship between illness perceptions and panic in chronic obstructive pulmonary disease. *Behaviour Research and Therapy*, *47*, 71–76. doi:10.1016/j.brat.2008.10.004
- Jones, F., Harris, P., Waller, H., & Coggins, A. (2005). Adherence to an exercise prescription scheme: The role of expectations, self-efficacy, stage of change and psychological well-being. *British Journal of Health Psychology*, *10*, 359–378. doi:10.1348/135910704X24798
- Kaptein, A. A., Scharloo, M., Fischer, M. J., Snoei, L., Cameron, L., Sont, J. K., ... Weinman, J. (2008). Illness perceptions and COPD: An emerging field for COPD patient management. *Journal of Asthma*, *45*, 625–629. doi:10.1080/02770900802127048
- Lawson, V. L., Bundy, C., & Harvey, J. N. (2008). The development of personal models of diabetes in the first 2 years after diagnosis: A prospective longitudinal study. *Diabetic Medicine*, *25*, 482–490. doi:10.1111/j.1464-5491.2008.02394.x
- Leventhal, H., Benjamin, Y., Brownlee, S., Diefenbach, M., Leventhal, E. A., Patrick-Miller, L., & Robitaille, C. (1997). Illness representations: Theoretical foundations. In K. J. Petrie & J. Weinman (Eds.), *Perceptions of health and illness* (pp. 19–45). London: Harwood Academic Publishers.
- Leventhal, H., Brissette, I., & Leventhal, E. A. (2003). The common-sense model of self-regulation of health and illness. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 42–65). New York: Routledge.

- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Contributions to medical psychology* (Vol. 2, pp. 7-30). New York: Pergamon.
- Leventhal, H., Nerenz, D., & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *Handbook of psychology and health: Social psychological aspects of health* (Vol. 4, pp. 219-252). Hillsdale, NJ: Erlbaum.
- Michie, S., O'Connor, D., Bath, J., Giles, M., & Earll, L. (2005). Cardiac rehabilitation: The psychological changes that predict health outcome and healthy behaviour. *Psychology, Health and Medicine*, 10, 88-95. doi:10.1080/13548500512331315398
- Moss-Morris, R., Sharon, C., Tobin, R., & Baldi, J. C. (2005). A randomized controlled graded exercise trial for chronic fatigue syndrome: Outcomes and mechanisms of change. *Journal of Health Psychology*, 10, 245-259. doi:10.1177/1359105305049774
- Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D., & Buick, D. (2002). The Revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health*, 17, 1-16. doi:10.1080/08870440290001494
- Nici, L., Donner, C., Wouters, E., Zuwallack, R., Ambrosino, N., Bourbeau, J., ... Troosters, T. (2006). American Thoracic Society/European Respiratory Society statement on pulmonary rehabilitation. *American Journal of Respiratory and Critical Care Medicine*, 173, 1390-1413. doi:10.1164/rccm.200508-1211ST
- Palange, P., Ward, S. A., Carlsen, K. H., Casaburi, R., Gallagher, C. G., Gosselink, R., ... Whipp, B. J. (2007). Recommendations on the use of exercise testing in clinical practice. *European Respiratory Journal*, 29, 185-209. doi:10.1183/09031936.00046906
- Petrie, K. J., Buick, D., Weinman, J., Cameron, L. D., & Ellis, C. J. (2002). Changing illness perceptions after myocardial infarction: An early intervention randomized controlled trial. *Psychosomatic Medicine*, 64, 580-586.
- Petrie, K. J., & Weinman, J. A. (1997). Illness representations and recovery from myocardial infarction. In K. J. Petrie & J. A. Weinman (Eds.), *Perceptions of health and illness: Current research and applications* (pp. 441-462). Amsterdam: Harwood Academic publishers.
- Rabe, K. F., Beghe, B., Luppi, F., & Fabbri, L. M. (2007). Update in chronic obstructive pulmonary disease 2006. *American Journal of Respiratory and Critical Care Medicine*, 175, 1222-1232. doi:10.1164/rccm.200704-586UP
- Ries, A. L., Bauldoff, G. S., Carlin, B. W., Casaburi, R., Emery, C. F., Mahler, D. A., ... Herrerias, C. (2007). Pulmonary rehabilitation: Joint ACCP/AACVPR evidence-based clinical practice guidelines. *Chest*, 131, 4S-42S. doi:10.1378/chest.06-2418
- Rothman, A. J. (2000). Toward a theory-based analysis of behavioral maintenance. *Health Psychology*, 19, 64-69. doi:10.1037/0278-6133.19.Supp1.64
- Rutter, C. L., & Rutter, D. R. (2007). Longitudinal analysis of the illness representation model in patients with irritable bowel syndrome (IBS). *Journal of Health Psychology*, 12, 141-148. doi:10.1177/1359105307071748
- Scharloo, M., Kaptein, A. A., Schlösser, M. A. G., Pouwels, H., Bel, E. H., Rabe, K. F., & Wouters, E. F. (2007). Illness perceptions and quality of life in patients with chronic obstructive pulmonary disease. *Journal of Asthma*, 44, 575-581. doi:10.1080/02770900701537438
- Scherer, Y. K., Schmieider, L. E., & Shimmel, S. (1998). The effects of education alone and in combination with pulmonary rehabilitation on self-efficacy in patients with COPD. *Rehabilitation Nursing*, 23, 71-77.
- Sears, S. R., & Stanton, A. L. (2001). Expectancy-value constructs and expectancy violation as predictors of exercise adherence in previously sedentary women. *Health Psychology*, 20, 326-333. doi:10.1037/0278-6133.20.5.326
- Sheldrick, R., Tarrier, N., Berry, E., & Kinsey, J. (2006). Post-traumatic stress disorder and illness perceptions over time following myocardial infarction and subarachnoid haemorrhage. *British Journal of Health Psychology*, 11, 387-400. doi:10.1348/135910705X71434
- Skinner, T. C., Carey, M. E., Cradock, S., Daly, H., Davies, M. J., Doherty, Y., ... Oliver, L. (2006). Diabetes education and self-management for ongoing and newly diagnosed (DESMOND):

- Process modelling of pilot study. *Patient Education and Counseling*, 64, 369–377. doi:10.1016/j.pec.2006.04.007
- Stockford, K., Turner, H., & Cooper, M. (2007). Illness perception and its relationship to readiness to change in the eating disorders: A preliminary investigation. *British Journal of Clinical Psychology*, 46, 139–154. doi:10.1348/014466506X115786
- Theunissen, N. C. M., de Ridder, D. T. D., Bensing, J. M., & Rutten, G. E. H. M. (2003). Manipulation of patient–provider interaction: Discussing illness representations or action plans concerning adherence. *Patient Education and Counseling*, 51, 247–258. doi:10.1016/S0738-3991(02)00224-0
- van Dijk, S., Scharloo, M., Kaptein, A. A., Thong, M. S. Y., Boeschoten, E. W., Grootendorst, D. C., ... Vos, P. F. (2009). Patients' representations of their end-stage renal disease: Relation with mortality. *Nephrology Dialysis Transplantation*, 24, 3183–3185. doi:10.1093/ndt/gfp184
- van Stel, H. F., Colland, V. T., Heins, N. L., Rijssenbeek-Nouwens, L. H. M., & Everaerd, W. T. (2002). Assessing inpatient pulmonary rehabilitation using the patient's view of outcome. *Journal of Cardiopulmonary Rehabilitation*, 22, 201–210. doi:10.1097/00008483-200205000-00013
- Watz, H., Waschki, B., Meyer, T., & Magnussen, H. (2009). Physical activity in patients with COPD. *European Respiratory Journal*, 33, 262–272. doi:10.1183/09031936.00024608

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