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ILLNESS PERCEPTIONS AND TREATMENT BELIEFS IN PULMONARY REHABILITATION FOR PATIENTS WITH COPD

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Illness perceptions and treatment beliefs in pulmonary rehabilitation for patients with COPD

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Sometimes, the fastest way to get there is to go slow.
Sometimes, if you want to hold on, you got to let go.
(Tina Dico, Count to ten)

CONTENTS

CHAPTER 1

General introduction

Background

The term Chronic Obstructive Pulmonary Disease (COPD) is used to refer to the related conditions emphysema, chronic bronchitis and chronic asthmatic bronchitis (WHO International Classification of Diseases (J40-J44)) [1]. COPD is defined as

"a preventable and treatable disease with some significant extrapulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterized by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious gases or particles" [2].

It is estimated that the prevalence of COPD is 9-10% among the adult population over 40 years of age [3] but many patients remain undiagnosed. In the Netherlands, 2.2% of all males and 1.7% of females are diagnosed with COPD, with a sharp increase after the age of 60 (See Figure 1 [4]).

The risk for developing COPD results from a gene–environment interaction. Tobacco smoke is the most important risk factor for the development of COPD. The traditional assumption that approximately 15% of all smokers will develop COPD appears to be an underestimation, since most smokers will develop COPD to some degree, depending on pack years and genetic susceptibility [5]. Non-smokers may also be at risk for developing COPD as a consequence of passive smoking, indoor and outdoor air pollution or occupational dusts and chemicals [6].

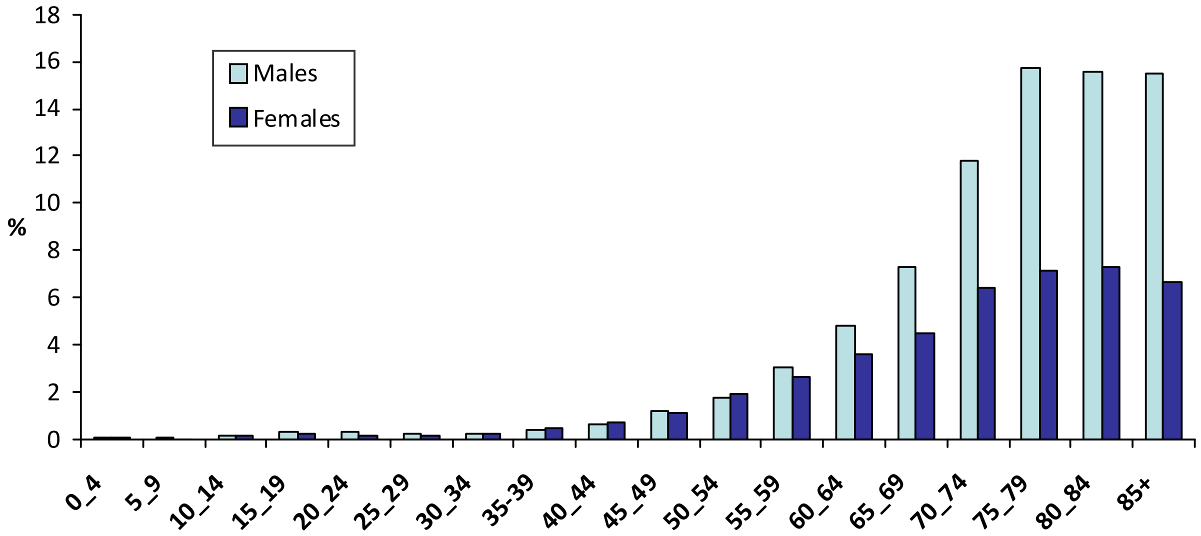

Figure 1. Prevalence of COPD in the Netherlands by sex and age

Patients with COPD typically suffer from chronic (and sometimes productive) cough, progressive dyspnoea and fatigue, leading to increased disability and reduced social participation as the disease progresses. Also, COPD is associated with considerable emotional burden. Roughly 10-20% of patients with stable disease suffer from symptoms of anxiety whereas 10-40% have symptoms of depression [7]. These figures are even higher for patients with advanced disease [7]. When present, anxiety and depression are more strongly associated with quality of life than indices of illness severity [8]. A more detailed description of epidemiology, risk factors, and psychological and social issues with regard to COPD is given in Chapter 2 of this thesis.

No cure for COPD exists at this time. Optimal management of COPD consists of careful monitoring of the disease, reducing exposure to risk factors such as tobacco smoke, management of stable disease and preventing and treating exacerbations [2]. According to the Global Initiative for Chronic Obstructive Lung Disease (GOLD), pulmonary rehabilitation is one of the main non-pharmacologic treatment modalities in the management of stable COPD, besides oxygen therapy and lung volume reduction surgery or lung transplantation [2].

Pulmonary rehabilitation

The principal goals of pulmonary rehabilitation are to reduce symptoms, improve patients' quality of life, and increase their physical and emotional participation in everyday activities [6]. Pulmonary rehabilitation combines cognitive and behavioural strategies such as physical exercise training, patient education, smoking cessation counselling, and nutritional and psychosocial interventions. Supported by research demonstrating its benefits, pulmonary rehabilitation has become a recommended standard of care for patients with chronic respiratory conditions [9]. There is ample evidence for the beneficial effects of comprehensive rehabilitation programmes on patients' functional capacity, dyspnoea, fatigue, emotional functioning and patients' sense of control over their condition [9,10].

However, in spite of the available support for the effectiveness of pulmonary rehabilitation, a considerable proportion of referred patients (20-40%) does not complete the rehabilitation programme [11-18]. Although medical and sociodemographic variables are partially accountable for suboptimal participation rates, it is generally assumed that patients' perceptions of illness and the subjective need for treatment play an important role in the motivation to follow treatment [19-22]. Within medical psychology these perceptions about health, illness and treatment are considered the cornerstone of human self-regulation.

Self-regulation

Self-regulation is commonly regarded as "a systematic process involving conscious efforts to modulate thoughts, emotions, and behaviours in order to achieve goals within a changing environment" [23:p750]. Although several different self-regulatory frameworks have been developed, each having their distinct features, they share a few basic assumptions [24] (see Box 1).

- Human behaviour is purposeful, aimed at achieving simple or more complex goals. Individuals will strive to achieve desired objectives and avoid unpleasant states.
- Motivation arises from a perceived discrepancy between a desired future state and present state.
- Cognitive and emotional processes are separate yet interrelated mechanisms contributing to human motivation.
- Motivation to achieve a goal or objective precedes planning and execution of efforts to achieve the goal.
- Coping efforts are accompanied by an appraisal process in which the outcomes of coping are reviewed.
- Self-regulation is cyclical. Appraisal of outcomes feeds back to previous stages. Individuals may decide the goal has been achieved, they may alter their strategy to achieve the desired state or they may give up their goal altogether if it is perceived as unattainable.

Box 1. Common assumptions within self-regulation theories.

One of the most influential self-regulation models specifically developed for illness behaviour is the Parallel Process Model (later referred to as Common Sense Model) [25-27], developed by Leventhal and colleagues. A central tenet within the CSM is that individuals are active, self-regulating problem solvers, who are motivated to avoid and cope with threats to their health [25]. Within this framework, patients' representations of illness guide the individual's effort to cope with a particular health threat or illness. The model follows the sequence of problem identification and interpretation, the planning and execution of coping efforts and finally the appraisal of the outcomes of the coping efforts (Figure 2).

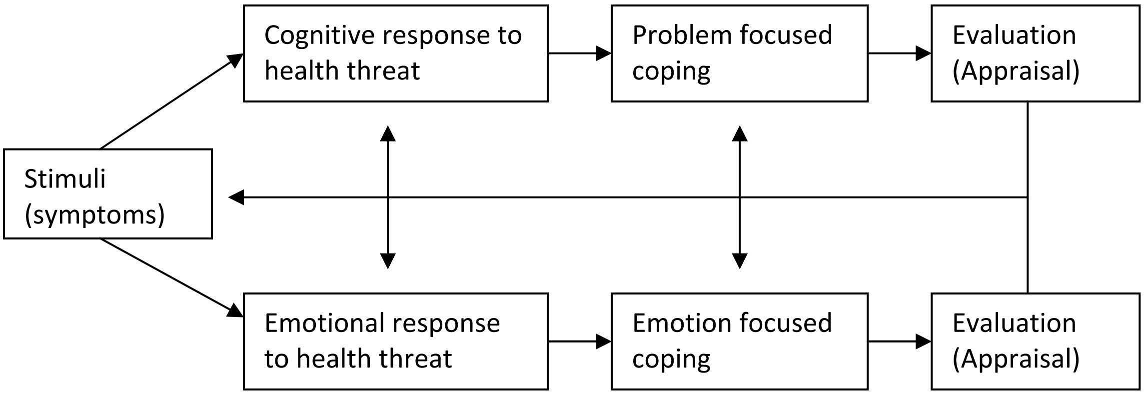

Figure 2. Parallel Process Model (adapted from Leventhal et al., 1997) [28]

The model proposes that when individuals are confronted with symptoms, this will evoke a cognitive response, with the aim of judging the seriousness and the controllability of the condition. Previous research has shown that individuals organise their beliefs about health conditions into five interrelated dimensions. These specific beliefs include the label and symptoms associated with the illness (illness identity), its cause, the perceived consequences for quality of life, the expected duration, and the degree to which one expects that the illness can be controlled or cured [29]. These attributes are thought to define the seriousness of the problem and set the direction for action. Closely linked to this cognitive process is a parallel emotional response, as the way in which individuals perceive their illness forms the basis for an affective reaction [26]. In self-regulation research, illness perceptions have been assessed by means of various methods such as generic (the Illness Perception Questionnaire (IPQ, IPQ-Revised & Brief IPQ)) [30-32] and illness specific questionnaires (e.g. Beliefs about Asthma Questionnaire (BAAQ), Personal Models of Diabetes Inventory (PMDI)) [33,34], or expressive methods such as patient drawings of their illness [35-38].

Secondly, based on the cognitive and the emotional representation of the health threat, individuals plan and execute a coping response. Coping efforts can be problem-focused (‘danger control’), such as following medical treatment or avoiding risks. Other strategies focus on the regulation of emotion (‘fear control’), for instance seeking social support or denying the problem.

In the third stage, individuals will review the outcomes of their coping efforts. Depending on the outcome of this evaluation the individual may choose to alter his or her coping response to achieve the desired state. Furthermore, not only is it hypothesized that this evaluation feeds back to the action state, it is also assumed that the original representations of the illness are shaped and reshaped by the success or failure of specific procedures for preventing, moderating and curing disease processes [29]. In other words, patients may adopt more positive beliefs about their condition if they judge their efforts to cope with the illness as successful, whereas disappointment may lead to less optimistic representations of the illness.

Over the last three decades a considerable amount of research has been dedicated to studying the influence of illness representations on coping and outcomes. However, empirical studies focusing on the appraisal stage of the CSM, to date, have been lacking [39].

Illness perceptions and adherence

The individual's decision to follow treatment can be regarded as a specific way of coping with an illness as perceived by the patient [40]. There is much empirical support for the role of patients' illness perceptions in adherence to treatment. Table 1 presents an overview of studies since 2000 that have examined associations of illness perceptions with treatment adherence. Results from the available studies indicate that the absence of distressing or unusual symptoms, a strong sense of personal controllability (making treatment adherence seem unnecessary), an episodic rather than continuous timeline of the illness, low confidence in the effectiveness of treatment and an intense emotional response to the illness are usually related to lower uptake or adherence to treatment.

Several studies have investigated the role of illness perceptions in cardiac rehabilitation programmes [41-46]. A meta-analysis showed that when cardiac patients associate their illness with more symptoms and perceive their condition to have negative consequences, while at the same time being convinced that their condition is manageable, they are likely to attend a rehabilitation programme [47].

In the population of patients with COPD, the relationship between illness perceptions and outcomes has been documented extensively (see Kaptein et al., 2008 for a review)[48]. By contrast, research about the relationship between illness perceptions and patients' coping behaviour is scarce although one study showed that patients' belief in the controllability of the illness was associated with better self-care when feeling well or when confronted with mild exacerbations [49]. To date, the role of illness perceptions in (adherence to) pulmonary rehabilitation has not been the subject of investigation.

Table 1. Association of illness perceptions with adherence

First author (year)	**Subjects**	**Adherence behaviour**	**Positive (+) or negative (-) association of illness perceptions with adherence**
Bucks (2009)[50]	Patients with cystic fibrosis	Routine courses of oral or nebulized antibiotics	Chronic timeline + Treatment control +
Dowson (2004)[49]	Patients with COPD	Self-care during exacerbations	Perceptions of personal control +
Halm (2006)[51]	Patients with asthma	Inhaled medication	Episodic timeline -
Hill (2007)[52]	Patients with musculoskeletal hand problems	GP consultation	More symptoms + More consequences + Chronic timeline + Emotional distress +
Horne (2002)[53]	Patients with asthma	Preventer medication	Consequences -
Jessop (2003)[33]	Patients with asthma	Preventer medication	Illness controllability +
Lawson (2004 & 2007)[34,54]	Patients with type 1 diabetes	Regular clinic attendance	Treatment control +
Llewellyn (2003)[55]	Patients with severe haemophilia	Prophylactic self-infusions	More haemophilia related symptoms +
Medina-Mirapeix (2009)[56]	Patients with chronic pain	Prescribed home exercises	Presence of symptoms + Poor prognosis expectations -
Molloy (2009)[57]	Older heart failure patients	Adherence to angiotensin-converting-enzyme Inhibitors	Chronic timeline - Consequences -
Ross (2004)[58]	Patients with hypertension	Oral medication	Consequences - Emotional distress - Personal controllability - Treatment curability +
Searle (2007)[59]	Patients with type II diabetes	Physical activity	Chronic timeline + Personal control +
Senior (2005)[60]	Patients with familial hypercholesterolaemia	Cholesterol lowering medication	Treatment control over familial hypercholesterolaemia +
Stafford (2008)[61]	Patients with coronary artery disease	Secondary prevention behaviours	Consequences +

Treatment perceptions and adherence

As an adjunct to the original work on illness perceptions, the role of patients' perceptions about treatment in adherence to treatment has more recently gained attention [62]. It is proposed that when patients have to make a decision about treatment, they first have to decide whether their condition is serious enough to require treatment. This process is influenced by representations of illness. Next, the individual has to review the available treatment options, weighing the salience of the expected benefits (treatment necessity) and negative consequences (treatment concerns) of each treatment option [63]. Patients' motivation to comply with treatment regimens is expected to increase when individuals have stronger perceptions of treatment benefits, whereas it is expected to decrease with greater treatment concerns. It can be expected that when patients are more adherent to the prescribed treatment regimen, they will experience greater benefits from treatment [62,64]. Many studies have found evidence for the role of perceived benefits and drawbacks in adherence to medication taking [50,53,65-68]. Others have related these perceptions to a variety of patient behaviours such as care seeking among patients with diabetes [54,69], self-care in cystic fibrosis [50], participation in an asthma self-management programme [70] or joining a cancer support group [71]. Again with regard to cardiac rehabilitation, several studies have found low perceived necessity and few expected personal benefits to be related to poor uptake and adherence [41,72-74]. Whether these perceptions are related to adherence in pulmonary rehabilitation has thus far not been investigated.

Perceptions and treatment outcomes

Research has demonstrated that treatment adherence can explain variations in treatment outcomes[64]. However, data on adherence are of little practical use to the clinician who wishes to predict at baseline which patients are likely to benefit from treatment[75]. It is therefore relevant to investigate if baseline perceptions predict response to treatment as has been proposed by Horne[62]. Thus far there has been some evidence suggesting that with regard to physiotherapy interventions, positive pre-treatment perceptions about the benefits of the intervention have been related to greater reductions in pain and reductions in medical care costs after treatment[76], whereas fear about physical activity is related to less improvement of disability after the intervention[77,78]. No studies yet have investigated the relation of treatment perceptions and outcomes in pulmonary rehabilitation.

Aim of this Thesis

Since previous studies in psychology as applied to medicine have provided support for the role of illness perceptions and treatment beliefs in patients' adherence to medical treatment, the aim of this thesis was to examine illness perceptions and treatment perceptions of patients with COPD in closer detail. Within the context of the Common Sense Model we have investigated how perceptions about

COPD and its treatment are related to drop-out and attendance in pulmonary rehabilitation and response to treatment. Specifically, the study will focus on four main research questions:

1) How do patients with COPD who are referred to a rehabilitation programme, perceive their illness and what do they expect from the rehabilitation programme?
2) How are perceptions of illness and treatment related to patients' drop-out and attendance in a pulmonary rehabilitation programme?
3) Do illness perceptions change after a rehabilitation programme, and is the individual's appraisal of the outcomes of rehabilitation related to one's post-treatment illness perceptions?
4) How are perceived treatment necessity and treatment concerns related to walking test results at baseline and at follow-up?

Outline of this thesis

Chapter 2 provides a general introduction to Chronic Obstructive Pulmonary Disease (COPD). Epidemiology, risk factors, treatment modalities, and physical and psychosocial impact of the disease are described. In the second part of the chapter a description of the aim, content, organisation and effects of pulmonary rehabilitation for patients with COPD is presented.

In Chapter 3 the results are described of interviews that were conducted with patients with COPD who had been referred to a rehabilitation centre for pulmonary rehabilitation. The aim of the qualitative study was to elicit patients' pre-treatment views regarding their illness and the rehabilitation programme.

Chapter 4 presents results of a prospective study on drop-out and non-attendance during a 12-week pulmonary rehabilitation programme. The first part of the study describes the causes for drop-out and non-attendance. The second part is concerned with examining the association of sociodemographic and clinical variables and patients' illness perceptions with drop-out and non-attendance.

The outcomes of a longitudinal study comparing pre- and post-treatment illness perceptions of patients who have completed a pulmonary rehabilitation programme are presented in Chapter 5. The aim of the study was to test assumptions within the Common Sense Model about the development of illness perceptions over time.

Chapter 6 presents the results of a study concerned with COPD patients' perceptions about treatment assessed before the start of the pulmonary rehabilitation programme. The chapter focuses on the role played by these perceptions on patients' baseline exercise test performance and the response to treatment.

The thesis concludes with a general discussion (Chapter 7) in which the results of the studies in this thesis are reviewed. Clinical implications and suggestions for research conclude this thesis.

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CHAPTER 2

Respiratory rehabilitation

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INTRODUCTION

Over the last decades, quality of life has become one of the main outcomes by which the effectiveness of medical treatment is determined. This development recognises the multidimensional character of illness. Especially in chronic illnesses, this multidimensional character is visible, as many patients have to deal with the behavioural, emotional, cognitive and social consequences of their disease. Rehabilitation programmes have been designed to address these consequences. In the field of respiratory diseases, comprehensive rehabilitation programmes (which comprise educational and pharmacological elements, breathing retraining and physical reconditioning) have been developed since the end of the 1960's (see Petty, 1993 for a historical review) and are now accepted by many respiratory physicians as a beneficial treatment for patients suffering from chronic airway obstruction (American Thoracic Society, 1999).

This chapter will focus on rehabilitation programmes for patients with chronic obstructive pulmonary disease (COPD). The first reason for this is that most patients who attend pulmonary rehabilitation programmes suffer from COPD (American Thoracic Society, 1999), Consequently, most research has been conducted on the effects of rehabilitation programmes for patients with COPD. The second reason is that benefits of pulmonary rehabilitation for patients with COPD and for patients with other respiratory disorders (such as cystic fibrosis, asthma and lung cancer) appear to be comparable (British Thoracic Society, 2001; American Thoracic Society, 1999).

This chapter will start with a description of COPD and its physical impact, followed by a discussion of the emotional, social and psychological consequences of COPD. The background, content and effects of respiratory rehabilitation will be described as well as a few comments with regard to the assessment of patients' physical and psychosocial functioning and the effects of intervention. Service and organisational aspects within the context of respiratory rehabilitation will be reviewed and the chapter will end with suggestions for future research.

EPIDEMIOLOGY AND PHYSICAL IMPACT

Definition of COPD

Chronic obstructive pulmonary disease (COPD) entails chronic bronchitis and emphysema. Together, these two disorders are characterised by "expiratory airflow limitation that is not fully reversible. This limitation is usually progressive and is related to inflammatory reaction of the lungs to noxious particles or gases" (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2004). Typical of chronic bronchitis are symptoms of persistent cough and sputum production. The large airways are inflamed and swollen. Breathing problems arise mainly as a consequence of the production of large amounts of mucus by the lining of the air tubes. For a clinical diagnosis, these symptoms must last for three months during two or more years.

Patients with emphysema suffer from chronic dyspnoea, especially during physical exercise as a result of damage to the walls of the air sacs (alveoli). This reduces the lungs' elasticity and decreases the ability to exchange oxygen and carbon dioxide. Recent epidemiological data (2003) indicate that most cases of COPD concern chronic bronchitis (approximately 75 per cent). Sixteen per cent of COPD patients suffer from emphysema and less than 10 per cent is diagnosed with both emphysema and chronic bronchitis (National Institutes of Health, 2003).

Prevalence

There is much variation in prevalence rates across the world, but most well-designed epidemiological studies in the Western world find a prevalence between 4 and 10 per cent among the adult population (Halbert, Isonaka, George, & Iqbal, 2003). These differences may be a result of actual variations in the occurrence of COPD, different definitions of COPD, characteristics of study samples (e.g. age of participants) and the use of spirometry to confirm COPD diagnosis. American statistics indicate that in 2000 an estimated 10 million persons were clinically diagnosed with COPD. However, spirometry tests among nearly 14,000 survey participants suggested that actual COPD prevalence may exceed 24 million, indicating that COPD may be highly underdiagnosed (Mannino, et al., 2002). Prevalence rates in Europe (UK, Italy, France, The Netherlands, Spain and Germany), among adults over 45 years of age, appear to vary between 6 and 8 per cent (Rennard et al., 2002).

Risk Factors

Tobacco smoke is the most important risk factor for the development of COPD. Studies show that approximately 80-90 per cent of the patients with COPD have been smoking and approximately 15 per cent of all smokers will develop COPD (Halbert et al., 2003). In those genetically susceptible to COPD, usually the disease will develop after smoking one pack of cigarettes (20 cigarettes) a day for 20 years (Stratelis, Jakobsson, Molstad, & Zetterstrom, 2004). More women than men have started smoking since the second half of the twentieth century. This has lead to an increasing prevalence rate of COPD in women. Apart from smoking behaviour, women may be at risk for COPD because of a potentially higher susceptibility to the effects of tobacco smoke compared to men (Varkey, 2004).

Non-smokers may be at risk as a consequence of passive smoking (Jaakkola, 2002). Other environmental factors that may contribute to the onset of COPD are air pollution, cooking on biomass fuels (e.g. wood, crop residues) occupational dusts and chemicals, and infections such as HIV and tuberculosis (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2004).

Mortality

According to the 2004 World Health Report, COPD is the fifth leading cause of death behind ischaemic heart disease, cardiovascular disease, lower respiratory infections and HIV/AIDS (WHO, 2004). In 2002, COPD was accountable for nearly 2.75 million deaths world-wide (261,000 in Europe). These world-wide mortality rates are more than twice as high as mortality rates resulting from lung cancer. Mortality rates resulting from COPD for men have been higher than for women in the past, but the increase in mortality has been higher for women over the last decades. In 2000, for the first time more women than men in the US died as a result of COPD (Mannino et al., 2002).

Morbidity and Co-morbidity

The global burden of COPD in terms of disability adjusted life years (DALY's), as an indicator of time lived with disability and the time lost due to premature mortality, is high and steadily increasing. Future health scenarios estimate that in 2020 COPD will be one of the most prominent causes of world-wide chronic morbidity, ranking fifth after ischaemic heart disease, unipolar major depression, road traffic accidents and cerebrovascular disease (Murray & Lopez, 1997). The high burden of COPD is also apparent from a healthcare system perspective. In the US, COPD has been responsible for over 13 million physician office visits in 2001 and 670,000 hospital admissions in 2002 (National Institutes of Health, 2004). In 2000, over one and a half million emergency department visits for COPD have been registered in the US (Mannino et al., 2002).

Patients with COPD are at risk for quite a range of concomitant diseases.
Van Manen and co-workers have explored the co-morbidity in patients with chronic airway obstruction (COPD and chronic asthma) older than 40 years of age, comparing them to age-matched controls without chronic airway obstruction. They found that patients with chronic airway obstruction suffer more often from ulcers, sinusitis, migraine, depression and cancer. High blood pressure and heart disease also appear to occur frequently in patients with airway obstruction, but not more often than in controls (van Manen et al., 2001).

Patients with COPD are particularly vulnerable to sleep problems. However, these problems remain largely unreported. Insomnia in COPD has many causes such as the presence of physical symptoms like sputum and cough, hypoventilation, disturbed gas exchange, and sleep deprivation caused by depression. Since many hypnotics also affect respiratory functioning, pharmacotherapy for sleep problems in patients with COPD needs to be applied with caution. Another often occurring dyssomnia is sleep apnoea. Together with hypoventilation, this may cause shortness of oxygen in the cardiovascular system and may be related to premature mortality (Kutty, 2004).

Physical Impact of COPD

COPD is often diagnosed at an advanced stage. A reason for this is that patients in the first stages do not necessarily experience symptoms. One of the first symptoms is cough, with or without sputum production. These symptoms are easily overlooked or considered not important. Dyspnoea is usually the first symptom that leads patients to consult a physician (Pauwels & Rabe, 2004). Dyspnoea is highly related to fatigue and these two are the most important symptoms experienced by patients with COPD (Meek & Lareau, 2004). In a recent study, nearly half of the patients with COPD stated to have problems with fatigue every day, compared to 13 per cent of the age- and sex-matched control group. Furthermore, the fatigue lasted for more than 6 hours per day in 53 per cent of the patients with COPD, compared to 19 per cent of the healthy controls (Theander & Unosson, 2004).

COPD is a systemic disease, which means that its effects can be found beyond pulmonary malfunctioning. Most frequent effects are abnormal systemic inflammation, nutritional abnormalities (changes in metabolism), weight loss and skeletal muscle dysfunction (Agustí et al., 2003). Osteoporosis is also frequently found in patients with COPD. As it increases the chance of fractures, it is a secondary cause of disability and mortality in COPD patients (Ionescu & Schoon, 2003).

REVIEW OF KEY EMOTIONAL, SOCIAL AND PSYCHOLOGICAL IMPACT

Emotional Impact of COPD

As COPD is a progressive disabling disease with little reversibility, it is not surprising that this disease is accompanied by a considerable psychological burden. In her review of studies about anxiety in patients with COPD, Brenes found that anxiety disorders occur more frequently in patients with COPD compared to the general population. The prevalence of generalised anxiety disorders (GAD) in patients with COPD appears to vary between 10 and 16 per cent, while prevalence of GAD in the normal population usually does not exceed 5 per cent. The occurrence of anxiety symptoms without a specific diagnosis is even higher (between 13 and 51 per cent). Panic attacks also occur often in patients with COPD. Prevalence rates of panic attacks appear to vary between 8 and 37 per cent (Brenes, 2003).

Although it is often said that COPD is a disease that is characterised by a high prevalence of depression, Van Ede and colleagues, in their review, were unable to reach a definitive conclusion about the exact prevalence of depression in their review of the literature, due to the many differences in the published studies (power/sample size, control group, screening instrument for depression and cut-off score). Ten epidemiological studies had a satisfactory methodological quality. These studies showed a large variation in prevalence rates (between 6 and 42 per cent) for depression among patients with COPD. Only two of the 10 reviewed studies were able to show a significantly higher prevalence of depression in comparison to matched controls (van Ede, Yzermans, & Brouwer, 1999). It appears that living alone, physical impairment and severity of airway obstruction are risk factors for depression in patients with COPD (van Manen et al., 2002). Not only do depression and anxiety have a negative effect on experienced quality of life but they also affect the patient’s motivation to quit smoking. It is therefore important for healthcare providers to be aware of signs of psychological problems when smoking abstinence is advised.

The occurrence of anxiety and depression does not only affect psychological well-being, it may also be strongly related to functional limitations. It appears that disease severity, as measured by forced expiratory volume (FEV_1) is not a strong predictor of functional status (e.g. general health, role functioning, social functioning, pain and vitality). However, patients’ levels of anxiety and depression (measured without somatic items) show strong associations with these indices of functional health (Kim et al., 2000).

Social Impact of COPD

Like many progressive chronic diseases, COPD affects patients as well as their social system. Patients’ roles within their family, as a partner, parent or grandparent may change, and family members and friends may be involved in caretaking over a long period of time. Withdrawal from labour force has its impact on the financial situation of the patient and his/her family, especially when the patient is the family’s main source of income. Symptoms such as productive cough, dyspnoea and the use of supplemental oxygen may lead to embarrassment which affects patients’ social interactions. In a large survey, over 60 per cent of the respondents with COPD indicated that their disease restricts them in their recreational activities and social outings (Rennard et al., 2002). Scharloo and colleagues also demonstrated that patients with COPD experience more limitations in social functioning, compared to a sample of healthy citizens over 60 years of age (Scharloo, Kaptein, Weinman, Willems, & Rooijmans, 2000). At the same time, patients appear to be concerned that others do not take their situation serious (Oliver, 2001). Some are anxious about openly speaking about their disease, because they anticipate on the public’s opinion that COPD is a self-inflicted disease. The absence of visible symptoms may create the fear of others seeing them as ‘frauds’, taking advantage of the situation (Nicolson & Anderson, 2003).

Although less studied, sexual activity may be hindered as a consequence of COPD. As a result of dyspnoea, cough, reduced muscle strength or anxiety, quality and/or frequency of sexual activity often decreases. In a qualitative study, nearly 70 per cent of the male patients with COPD indicated some type of sexual problem (i.e. reduced libido or erectile problems). Most partners were less satisfied with the relationship than patients. Dissatisfaction in partners appeared to be a result of communication problems (e.g. irritability on the part of the patient and continuous arguments), rather than of patients sexual dysfunction (Ibañez et al., 2001).

Psychological Impact of COPD

The systemic effects of impaired oxygen exchange affect neurological and cognitive functioning. Antonelli Incalzi and colleagues found that patients with COPD, as compared to age-matched controls, showed significant impairments in immediate and delayed recall of information (i.e. short- and long term memory), attention span and recognition. Additionally, it was demonstrated that impairments in long-term memory and overall cognitive functioning were both associated with lower medication adherence (forgetting to take prescribed medications at least twice a week) (Antonelli Incalzi et al., 1997).

The psychological effects of COPD may also be apparent from patients’ self- concept. Becoming dependent (e.g. on medication or the support and understanding of others) has serious consequences for the patients’ self-esteem. Patients tend to gradually experience themselves as different from the person they were before, which is often accompanied by feelings of loss and distress. In addition, self-esteem may be undermined by feelings of self-blame and the sense of being a burden to others (Nicolson & Anderson, 2003).

Another important psychological concept that is seriously compromised in COPD is patients’ self-efficacy (i.e. the subjective judgement of capability to perform functional activities). As a consequence of physical symptoms (mainly dyspnoea), patients’ confidence to perform desired activities without experiencing breathing problems often declines (Scherer & Schmieder, 1997). Self-efficacy appears to be closely related to perceived quality of life, even when controlling for the effect of medical (pulmonary function, respiratory symptoms, duration of illness) and sociodemographic variables (age, previous occupation) (McCathie, Spence, & Tate, 2002).

BACKGROUND, CONTENT AND BENEFITS OF PULMONARY REHABILITATION

Definition of Pulmonary Rehabilitation

No cure for COPD exists at this time. Therefore, increasing or maintaining quality of life is one of the most prominent goals in healthcare. According to the GOLD recommendations, pulmonary rehabilitation is one of the main non-pharmacological treatment modalities. Besides oxygen therapy and lung volume reduction surgery or lung transplantation, rehabilitation plays an important role in the management of stable COPD (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2004).

Pulmonary rehabilitation can be described as “a multidisciplinary program of care for patients with chronic respiratory impairment that is individually tailored and designed to optimize physical and social performance and autonomy” (American Thoracic Society, 1999). As stated by the Global Initiative for Chronic Obstructive Lung Disease (GOLD), the goal of rehabilitation is to reduce symptoms, improve quality of life and increase physical and emotional participation in everyday life (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2004).

Components of Rehabilitation

The emphasis on a comprehensive approach is the reason for the many components that are present in a rehabilitation programme. Physical exercise and education are core components in rehabilitation programmes. Other components such as smoking cessation modules, relaxation and energy conservation exercises, cognitive-behavioural interventions and nutritional advice and support are less frequently added to the programme (British Thoracic Society, 2001). Below, the individual components in pulmonary rehabilitation are described in detail.

Physical Training

Most frequently applied exercises in rehabilitation are lower and upper extremity endurance training, (respiratory) muscle strength training and breathing exercise. The endurance training includes walking or cycling and lifting weights or stretching elastic bands (American Thoracic Society, 1999). These exercises usually are performed at a percentage (>60 per cent) of the maximum capacity. Over the course of rehabilitation, duration or intensity of the exercises can be gradually increased (British Thoracic Society, 2001). Respiratory muscle strength training aims to reverse deterioration of muscle strength, which is a cause of dyspnoea and exercise limitation. Breathing techniques, such as pursed-lip breathing and diaphragmatic breathing aim to increase tidal volume and to reduce breathing frequency.

Education

Education in rehabilitation aims to increase patients' comprehension of the physical and psychosocial consequences of their disease. Increased knowledge is thought to facilitate patients' active participation in the management of their disease. Most rehabilitation programmes comprise an educational component. However, the content of the educational classes may vary. A classification can be made in medical/physiological topics (e.g. pathology and pharmacology, breathing techniques, nutritional advice, exacerbation management) and psychosocial or behavioural topics (e.g. smoking cessation, energy conservation, goal setting, coping, relaxation, self-management, social and intimate relationships) (American Thoracic Society, 1999; British Thoracic Society, 2001).

Psychosocial Interventions

Besides the provision of psycho-education, specific cognitive or behavioural interventions can be part of a rehabilitation programme. Different from the education component, these interventions are individually tailored depending on the patients' needs. A treatment strategy is formulated during the intake on the basis of a formal assessment of psychological and social well-being. There is a wide array of interventions that are applied in the context of pulmonary rehabilitation. Frequently used techniques are cognitive and behavioural interventions, self-management techniques (monitoring, realistic goal-setting, contracting and stimulus control) relaxation training (aimed at reducing stress and conserving energy) and coping skills training (promoting a positive and problem-focussed way of handling their condition). An example of assessment and psychosocial interventions within the context of pulmonary rehabilitation can be found in Box 1.

Mr. Jones, a widower of 64 years, has been referred to an outpatient pulmonary rehabilitation clinic by his respiratory physician. Three years ago he was diagnosed with emphysema. Complaints about fatigue and reduction in activities were the main indication for referral. Standard psychological assessment during the intake includes the SCL-90 questionnaire, from which it became apparent that Mr. Jones quite often suffers form depressive thoughts. In the intake interview with the social worker, Mr. Jones explains he is, to a large extent, house-bound as a result of lack of energy. The decrease in mobility and reduction in social activities turned out to be the cause of his depressive feelings. Furthermore, he has trouble doing household chores by himself, such as cleaning and cooking. He experiences feelings of guilt and self-blame as he has been a heavy smoker. At the same time he admits he finds it hard to express these feelings to other people.

It is agreed that during the rehabilitation the clinical psychologist will have a few sessions with Mr. Jones about the origins of guilt and self-blame. The aim is to educate Mr. Jones about the destructive nature of these negative thoughts, as they influence his motivation and outlook. In collaboration with Mr. Jones, the training staff will formulate realistic and achievable goals for the rehabilitation programme in terms of functional capacity, in order to boost his self-confidence. The social worker will apply for home-care services as well as a private parking lot near to Mr. Jones' home. Group sessions on self-management are a standard element in the programme. It is expected that Mr. Jones may learn how others cope with practical and psychosocial difficulties. One session specifically deals with problems and solutions in maintaining social contacts. In these sessions Mr. Jones will be encouraged to express his concerns in a safe environment, but also to share his self-developed strategies for self-care.

As part of a smoking cessation intervention, Mr. Jones is asked to sign a 'no-smoking contract'. Additionally he will be assisted in his attempt with nicotine replacement therapy and counselling by the social worker during the programme. After the end of the programme, Mr. Jones' family physician will continue the provision of support and counselling in relapse prevention.

Box 1.

Patient Selection

Patients eligible for rehabilitation are those who suffer from dyspnoea, reduced exercise tolerance and/or a restriction in activities. The need for rehabilitation should be determined by the level of impairment and subjective burden rather than by physiological indices of pulmonary functioning (American Thoracic Society, 1999). This indicates that pulmonary rehabilitation programmes are not designed for one type of pulmonary disease. Donner and Lusuardi state that patients with severe deconditioning, muscle weakness and exercise intolerance are prime candidates for participation (Donner & Lusuardi, 2000).

Rehabilitation programmes are not recommended for patients who suffer from serious co-morbidity (severe heart failure, non-respiratory cancer or neuromuscular disorders) and limited ability to learn/cognitive impairment (American Thoracic Society, 1999). The discussion about whether to in- or exclude smokers is still ongoing. However, there is no evidence that smokers would not benefit. Most programmes include smokers if they are prepared to quit or follow a smoking cessation programme (American Thoracic Society, 1999; British Thoracic Society, 2001).

Setting and Duration of Pulmonary Rehabilitation

Three different settings for rehabilitation programmes are usually distinguished. In an outpatient setting, patients visit a hospital or community centre a few (usually two to three) times a week for exercise and education sessions. When travelling is too difficult, home-based programmes may be an alternative. Physiotherapists provide patients with exercise and education in their own environment. Inpatient settings are used for patients with the most profound physical impairments who need intensive nursing and monitoring (American Thoracic Society, 1999). Outpatient programmes are usually less expensive than inpatient or home-based programmes. However, they require additional motivation and resources with regard to transport.

The optimal duration of a pulmonary rehabilitation programme is not yet determined, but most programmes take between six and 12 weeks. There is some evidence that a longer duration is associated with greater improvements in physical and psychological functioning (Rossi et al., 2005).

Impact of Rehabilitation on Physical Disabilities

Pulmonary functioning, as measured by the maximal volume of air that can be forcibly exhaled (forced vital capacity, FVC) and the maximum amount of air exhaled in one second (forced expiratory volume, FEV_1), does not improve as a result of pulmonary rehabilitation (Devine & Pearcy, 1996; Emery et al., 1998). Still, in the absence of improvement of lung function, rehabilitation leads to many improvements in the functional domain. Lacasse and co-workers conducted a meta-analysis on the short term effects of 23 pulmonary rehabilitation programmes on quality of life and exercise capacity. Their review included only randomised controlled studies comparing rehabilitation programmes (in-patient, out-patient or home-based) with conventional care. Interventions were included in the review if they consisted of exercise training with or without education or psychosocial support. Maximal exercise capacity (14 reviewed studies measuring improvements on the cycle ergometer test) and functional exercise capacity (10 reviewed studies measuring outcomes on six-minute walk distance) showed significantly greater improvement in rehabilitation groups compared to the control groups. Also, a larger decrease in feelings of fatigue and dyspnoea was found in patients who had attended rehabilitation programmes, compared to patients who had received usual care (Lacasse et al., 2001). Another meta-analysis showed that pulmonary rehabilitation improved exercise endurance (time and/or distance patients are able to walk or cycle) and reduced the restrictions that patients experience in activities of daily living (Devine & Pearcy, 1996).

To date, there is no convincing evidence that disease related aspects, such as number and severity of exacerbations and healthcare use, are affected by education or self-management programmes as a single intervention (outside the context of comprehensive pulmonary rehabilitation) (Monninkhof et al., 2002).

It is also still unclear whether pulmonary rehabilitation affects survival of patients with COPD (Troosters, Casaburi, Gosselink, & Decramer, 2005). However, the important effects of rehabilitation on functional status and walking ability may be related to longer survival, as these indices are stronger predictors of survival than traditional measures of disease severity, such as one-second Forced Expiratory Volume (FEV_1) or need for supplemental oxygen (Bowen et al., 2000).

Impact of Rehabilitation on Emotional Well-being

Besides positive effects on exercise capacity, comprehensive rehabilitation programmes have demonstrated beneficial effects on psychosocial well-being. Withers et al. (1999) showed that a six-week outpatient pulmonary rehabilitation programme, consisting of exercise training, education, psychosocial support and stress management, decreased depression and anxiety scores among patients with COPD. Moreover, at 6-month follow-up these improvements were still present (Withers, Rudkin, & White, 1999). Similar improvements in depression and anxiety scores were found in patients who had completed a rehabilitation programme that comprised physical exercise, educational lectures (e.g. regarding anatomy of lungs and pathophysiology of COPD) and stress management (which included relaxation techniques and cognitive restructuring). Patients who had completed an education plus stress-management intervention without the physical exercise did not show improvements in psychological well-being, indicating the importance of exercise (Emery et al., 1998). Interestingly, their results indicate that in the groups of patients who had received education without exercise, greater disease knowledge was associated with increased anxiety. The finding that a combination of education plus exercise yields positive results for well-being and emotional functioning was further supported by the meta-analysis by Devine and Pearcy (Devine & Pearcy, 1996).

In their review of randomised controlled studies of psychosocial interventions as part of pulmonary rehabilitation, Kaptein and Dekker (2000) conclude that most of the applied psychosocial interventions consist of relaxation training. Only on a few occasions, cognitive-behavioural modification, coping training and stress-management were offered. All 10 reviewed studies showed significant improvements in the psychosocial domain (e.g. self reported QoL, dyspnoea, well-being, reduced social disability and increased self-efficacy) (Kaptein & Dekker, 2000). The popularity of relaxation training may be explained by the fact that the techniques are easy to learn and are inexpensive to deliver (e.g. on CD or audiocassette) (Devine & Pearcy, 1996).

Atkins and colleagues tested the effectiveness of behavioural and cognitive interventions in promoting adherence to an individual exercise regimen in patients with COPD (Atkins, Kaplan, Timms, Reinsch, & Lofback, 1984). After patients had received a personal walking programme, they were assigned to one of three intervention conditions, an attention only condition or no-treatment control condition. In the cognitive intervention, patients were instructed to monitor negative thoughts and feelings and were taught to replace these by positive ones in order to motivate them during exercising. The behavioural intervention consisted of several self-management techniques (keeping a daily schedule, signing a contract and self reinforcement) as well as relaxation training and breathing exercises. A third intervention combined both behavioural and cognitive interventions. This approach enabled the researchers to determine the individual contribution of each intervention to patients' adherence, perceived self-efficacy and well-being. The results showed that adherence to exercise regimen (as measured by time spent walking) greatly improved after a combined cognitive-behavioural intervention. Furthermore, patients' self reported quality of well-being (representing mobility, physical activity and social activity) increased in patients who had undergone a behavioural, a cognitive or a combined cognitive-behavioural intervention. Patients in an attention-only control or no-intervention condition reported a decrease in well-being scores after three months (Atkins et al., 1984).

De Godoy & De Godoy have studied the benefits of an additional cognitive psychotherapy module (addressing patients' psychosocial needs and thoughts about marriage, work, health and interpersonal relations) in a 12-week rehabilitation programme. Although the sample was very small (intervention n=14 vs. control n=16), the experimental group showed a significant reduction in anxiety (BAI) and depression (BDI) scores, which was not apparent in controls who followed the same rehabilitation programme without the psychotherapy sessions (de Godoy & de Godoy, 2003).

Kunik and colleagues designed a two-hour group therapy session for older patients with COPD. This session comprised psycho-education (the role of anxiety and depression in chronic illness), relaxation exercises and cognitive-behaviour interventions (redirecting maladaptive thoughts, and encouraging exposure to anxiety provoking situations/reducing behaviour that maintains anxiety). Patients received a booklet with practice exercises regarding coping skills and an audiotape containing the educational material. Additionally, these patients were called weekly by the staff to provide an opportunity to ask questions and to monitor and enhance compliance with the coping skill exercises. After six weeks, anxiety and depression had been reduced, compared to patients who had been assigned to a education only control group (Kunik et al., 2001).

However, not all studies on psychotherapy for patients with COPD yield positive results. For instance, a pilot study consisting of six 90 minute sessions of cognitive behavioural therapy, focussing on the origin of anxiety, the development of psychological coping styles and instruction of relaxation and distraction techniques, did not affect anxiety and depression (HADS) or quality of life of 10 participants (St. George's Hospital Respiratory Questionnaire) (Eiser, West, Evans, Jeffers, & Quirk, 1997). After three sessions, a different therapist took over the sessions, which may have reduced the potential effect of the intervention.

Blake and colleagues studied the effects of a psychosocial intervention for patients who had been referred to a pulmonary clinic (Blake, Vandiver, Braun, Bertuso, & Straub, 1990). Stress reduction techniques included relaxation, breathing exercises, visual imagery and cognitive restructuring. By making a plan for increasing social and (recreational) activities with family members and friends, the intervention aimed to increase patients' perceived social support and social participation. Unfortunately, compared to the control condition, the intervention was not able to result in a significant improvement in morbidity outcomes (e.g. hospital days, restricted activity days) after 6 and 12 months. Psychosocial and physical functioning (Sickness Impact Profile) did not improve after six months. However, after 12 months the intervention group showed a higher physical function status than the control group (SIP). According to the authors, insufficient sample size may have been responsible for the lack of effect. Table 1 provides an overview of psychosocial interventions for patients with COPD.

Table 1. Effect of psychosocial interventions for patients with COPD.

First author	Intervention	Results
Atkins, 1984	Walking regimen + Behaviour modification (BM) or Cognitive modification (CM) or Cognitive + behaviour modification (CBM)	For all three interventions: Health status (QWB) ↑ Efficacy expectations (walking distance) ↑ Adherence (time spent walking) ↑ Exercise tolerance ↑ CBM shows more improvement than BM or CM for time spent walking
	Control groups: attention only and no intervention	Control groups: QWB ↓
Blake, 1990	Stress management (relaxation techniques, breathing exercises, visual imagery, cognitive restructuring) follow up telephone contact	No improvement in morbidity, psychosocial and physical functioning after 6 months After 12 months: physical function and total function (SIP) ↑
	Control group: no intervention	Control group: no improvement
Emery, 1998	Exercise (EX) + education (E) + stress management (SM)	Depression (SCL-D)↓ Anxiety (SCL anxiety) ↓ QoL (SIP)↑ Verbal fluency (Halstead-Reitan) ↑
	Control group: (E) + (SM)	Control group: no improvement
Eiser, 1997	Exploration of roots of anxiety. Deep breathing techniques, muscle relaxation, distraction techniques.	6MWD ↑ No improvement in anxiety and depression (HADS), dyspnoea (VAS) or quality of life (SGRQ)
	Control group: no intervention	Control group: no improvement
De Godoy, 2003	Standard programme (physical exercise, education, relaxation techniques, breathing exercises) + psychotherapy	Anxiety (BAI) ↓ Depression (BDI) ↓ 6MWD ↑
	Control group: standard programme	Control group: 6MWD ↑
Kunik, 2001	CBT: psycho-education, skills training (relaxation, thought stopping, recognizing maladaptive thoughts), exposure and practice exercises. Follow up telephone contact	Anxiety (BAI) ↓ Depression (GDS) ↓ Mental health (SF-36) ↑ Other 7 dimensions of SF-36 did not improve
	Control group: education	control group: no improvement
Withers, 1999	Exercise training, education, psychosocial support, stress management	Depression (HADS) ↓ Anxiety (HADS) ↓

Note. ↓: reduction, ↑: improvement

Impact of Rehabilitation on Social Well-being

The effects of pulmonary rehabilitation on social functioning are largely understudied.
In a review by Maillé and colleagues on quality of life studies in chronic lung diseases, none of the included 43 studies from 1980-1994 evaluated the effects of rehabilitation on social functioning (Maillé, Kaptein, de Haes, & Everaerd, 1996). One major problem is that only a limited proportion of the empirical studies have used a measurement instrument which included a specific social functioning subscale.

One study that reported effects on social functioning was conducted by Fuchs-Climent and co-workers. In this study a three-week inpatient pulmonary rehabilitation programme for patients with COPD was organised. The programme consisted of health education (information about the disease, discussions about healthy daily living strategies and psychosocial problems linked to the disease), respiratory therapy with aerosol and/or drainage and physical exercise. Apart from improvements in mobility, energy and emotional reactions, participants reported a decrease in feelings of social isolation (measured by the Nottingham Health Profile) (Fuchs-Climent, Le Gallais, Varray, Desplan, Cadopi, & Préfaut, 1999).

Increased physical health as a result of rehabilitation may pave the way for restoration of social functioning. However, social interactions within the programme may also be valuable for patients, especially for those who live alone. Monninkhof and colleagues conducted interviews with 20 participants in a self management programme. These patients considered the training and education as a social activity in itself and appeared to benefit from the social support by staff and other patients (Monninkhof et al., 2004). This may be of particular importance as patients often feel they are not taken seriously by their own social network.

By increasing overall activity tolerance, rehabilitation may also reduce some physical barriers to sexual activity. However, Curgian and Gronkiewicz advise that when discussing sexuality with patients it is important to explain that sexual activity will be accompanied by dyspnoea. It is important to convince patients and their partners that dyspnoea during sex is no more dangerous than in other activities (Curgian & Gronkiewicz, 1988). Furthermore, an intervention that aims to help patients and their partners adapt to the disease and reduce interpersonal conflicts may be more effective than an intervention which focuses solely on sexual problems (Ibanez et al., 2001).

Impact of Rehabilitation on Psychological Well-being

Studies on effects of exercise on cognitive processes are rather scarce, but there is some evidence that the combination of exercise, education and stress management can improve cognitive performance (verbal fluency) (Emery et al., 1998; Emery, Honn, Frid, Lebowitz, & Diaz, 2001).

Self-efficacy also appears to be amenable to intervention. Scherer and Schmierer were able to demonstrate improvement in patients' sense of self-efficacy in an outpatient rehabilitation programme. In addition to physical exercise and education, specific interventions with regard to self efficacy consisted of: realistic goal setting, observational learning (seeing how others perform a comparable task), encouragement and praise when successfully performing a specific activity and stress-management (relaxation training) (Scherer & Schmieder, 1997). Similar improvements in self-efficacy were obtained as a result of cognitive and behavioural interventions in the Atkins study (Atkins et al., 1984).

COMMENTARY ON PSYCHOLOGICAL ASSESSMENT, FORMULATION AND INTERVENTION.

Assessment of Physical and Psychosocial Functioning

According to the BTS, 'the outcomes of rehabilitation should be observed with the appropriate measures of impairment, disability and handicap' (British Thoracic Society, 2001). It is important to note though, that the choice of measurement instruments may affect the results that are obtained. Generic health status instruments (such as the MOS SF-36, Nottingham Health Profile, and Sickness Impact Profile) allow for comparison between patient groups and yield a single summary score but may be less responsive (the ability to detect improvements after intervention) than specific measures (Guyatt, Stubbing, Goldstein, King, & Feeny, 1999).

Most widely used specific measurement instruments are the St. George's Hospital Respiratory Questionnaire (SGRQ) and the Chronic Respiratory Questionnaire (CRQ). The SGRQ has three dimensions: respiratory symptoms, activities limited by, or causing, breathlessness, and psychosocial impact on daily life. The CRQ has four subscales: dyspnoea, fatigue, emotional functioning and mastery. The CRQ focuses on limitations in activities that are important to the individual patient, whereas these items are standardised in the SGRQ. However, data comparing the responsiveness of both instruments do not clearly favour one over the other (Jones, 2001).

Assessment of patients' emotional functioning is complicated for two reasons. Firstly, epidemiologic studies use many different measurement instruments, making a comparison between these studies very complicated. Secondly, symptoms of psychopathology (e.g. sleep problems, fatigue, loss of vitality or appetite) are common in patients with COPD, but they are not necessarily related to affective disorders. It is therefore important to use an instrument that does not refer to somatic complaints (e.g. HADS) or to control for these confounding variables in the analysis of psychological problems.

Assessment of Effectiveness of psychosocial Interventions

The interventions aimed to reduce psychosocial burden often comprise multiple techniques (e.g. relaxation therapy, physical exercise, stress management, education, cognitive-behavioural therapy). This makes it difficult to determine the effectiveness of each separate component. Also, most intervention studies use small samples. This decreases the power to detect significant results (Brenes, 2003). Meta-analyses are used to compare the results of several studies. However, as many programmes use different approaches to treat of psychological problems and different instruments to measure improvement, meta-analyses are often not possible (Rose et al., 2002).

Long-term Effects of Rehabilitation

Rehabilitation programmes have been able to show improvement in many aspects of quality of life. However, the usefulness of the intervention is debatable when the effects are only observable immediately after the programme. Training effects are reversible, which means that they are maintained only so long as exercise is continued. Post-rehabilitation supervision programmes, designed to encourage patients to adhere to the training regimen after the formal rehabilitation programme, may sort effect as was shown by Ries and co-workers (Ries, Kaplan, Limberg, & Prewitt, 1995). However, these follow-up programmes themselves have a fixed duration so their long-lasting effects have not been unequivocally demonstrated yet (Wempe & Wijkstra, 2004). In order to obtain maintenance of effect, Troosters and colleagues, advise weekly strenuous exercise sessions, preferably supervised by a physiotherapist, following pulmonary rehabilitation (Troosters et al., 2005).

Strijbos and colleagues have suggested that home-based rehabilitation programmes may be superior to outpatient programmes in producing long-term effects. The initial improvements of outpatient rehabilitation on exercise capacity and dyspnoea had returned to baseline levels after 12 months. However, the improvements of home-based rehabilitation were still significant at 18 months. One explanation for this difference is that as patients get accustomed to exercising at home, this would make it easier for them to continue the exercise regimen after the formal rehabilitation programme (Strijbos, Postma, Altena, Gimeno, & Koëter, 1996).

Summary and Suggestions for Future Interventions

In an attempt to integrate the results from previous research in the field of pulmonary rehabilitation, we will end this commentary with some recommendations for the content and organisation of pulmonary rehabilitation programmes.

It is believed that the physical symptoms of fatigue and dyspnoea lead to reduced exertion tolerance and consequently a reduction in (social) activities. In turn, refraining from physical activity is thought to be responsible for an additional deterioration of exercise tolerance. This may cause the patient to enter a downward spiral. An important goal of rehabilitation is to break this vicious circle.

Rehabilitation programmes with a comprehensive approach, in our view, will produce the greatest improvement. By comprehensive, we mean that rehabilitation programmes fair best with a holistic approach, acknowledging the interaction between physical, behavioural, emotional and cognitive processes.. It appears that most interventions that combine physical exercise training with psychosocial interventions produce favourable results in psychological well-being (mostly anxiety and depression). However, interventions without a physical component are not able to show such improvement (c.f. Blake et al., 1990; Eiser et al., 1997; Emery et al., 1998). Exercise training is therefore a necessary, but not sufficient, element in the attempt to optimise patients' quality of life. Psychologists, as part of a multidisciplinary team, can play an important role in treatment of several common problems (anxiety/depression, adjustment problems, non-compliance to treatment, neuropsychological problems, social/marital problems, end of life decisions and conflicts between patient and healthcare provider) (Labott, 1998).

Besides comprehensive, a programme should be individually tailored. By tailored, we mean that the programme should incorporate patients' individual goals and motivation. The available resources in a rehabilitation programme should be incorporated, depending on the goals of the individual (Sivaraman Nair, 2003). Involving patients in goal setting during rehabilitation and adjusting the programme to individual needs may enhance compliance to treatment regimen and sustain of gains made.

Behavioural change, and especially maintenance, is a key factor in long-term effects. It is important to discuss motivation and possibilities for continuation at the end of a rehabilitation programme (for example at a physiotherapy practice). The transition to everyday life without the supervision and reinforcement by staff members is a critical moment and continuation of exercises appears to be very difficult (Cicutto, Brooks, & Henderson, 2004). In our opinion, the involvement of the social network (family members, friends, other patients) during and after rehabilitation is of particular importance in prevention of relapse.

SERVICE AND ORGANISATIONAL ASPECTS.

Organisation of Pulmonary Rehabilitation

World-wide there appear to be differences in the organisation of pulmonary rehabilitation programmes. In 1998, Kida and colleagues studied content and organisation of these programmes in North America, Europe and Japan. Pulmonary rehabilitation programmes were available at 56 per cent of hospitals in North America and 74 per cent of the hospitals in Europe, but at only 20 per cent of hospitals in Japan. Most rehabilitation programmes were conducted in an outpatient setting in North America (98 per cent), whereas both outpatient (55 per cent) and inpatient programmes (65 per cent) were adopted in Europe. The high cost of inpatient programmes and different healthcare insurance systems in North America and Europe may be responsible for this difference. More than 80 per cent of the patients in European and North American pulmonary rehabilitation programmes suffered from COPD. In Japan this percentage was 34 per cent. Other frequent conditions are tuberculosis (28 per cent) and bronchial asthma (16 per cent). Finally, important differences were found in the components that were incorporated in North American, European and Japanese programmes. Family education, nutritional instruction, treadmill, walking training, and increasing the activity of daily living were elements that were more often used in North American rehabilitation programmes than in European or Japanese programmes (Kida, Jinno, Nomura, Yamada, Katsura, & Kudoh, 1998).

Recently, Yohannes and Connnolly have investigated the pulmonary rehabilitation programmes in the UK. Approximately 40 per cent of the hospitals with a physiotherapy department in the UK run a pulmonary rehabilitation programme (Yohannes & Connolly, 2004). These programmes usually have an outpatient setting. Usually patients visit the outpatient centre twice a week for a period of eight weeks, though the range in programme duration varies considerably (5-24 weeks). Besides COPD patients, asthmatic patients are frequently (in 68 per cent of the centres) included. Exercise training and education are used in more than 90 per cent of the programmes. Other frequent components are nutritional support (87 per cent), relaxation training (84 per cent) and training in activities of daily living (81 per cent). Ninety percent of the rehabilitation centres accept smoking patients, but only half offer smoking cessation support in their programme. Interestingly, patients that participate are relatively younger. Only 10 per cent of the centres report a mean age over 70. Lack of awareness about rehabilitation among geriatricians and morbidity among older patients may explain the low proportion of older patients in rehabilitation. Overall, it is estimated that less than 1.5 per cent of the COPD population in the UK has access to pulmonary rehabilitation.

Drop-out in Rehabilitation.

Although the effects of rehabilitation on several components of quality of life have now been demonstrated, a substantial proportion of the eligible patients fail to enter or complete rehabilitation programmes. Only limited research has been conducted on the psychosocial factors that may contribute to non-adherence in pulmonary rehabilitation programmes. Young and co-workers investigated possible factors that contribute to non-adherence during a four-week outpatient pulmonary rehabilitation programme for moderate-to-severe COPD patients. Of the 91 participants in the study, 30 (33 per cent) did not begin the programme and six (7 per cent) did not finish the programme. Factors that were related to non-adherence were: being divorced, living alone and living in a rented accommodation. Furthermore, smokers were more likely to be non-adherent. No differences were found in terms of physiological measures (body mass index, perceived dyspnoea, FEV_1, FVC and 6-min walk distance) or psychological variables (such as depression, anxiety or a tendency to experience hyperventilation). Those who were less satisfied with disease-specific social support were also characterised by non-adherence. Perceived general social support turned out to be unrelated to adherence (Young, Dewse, Fergusson, & Kolbe, 1999).

Shenkman (1985) conducted a study to identify factors that are associated with attrition in a pulmonary rehabilitation programme. Forty patients with COPD entered a nine-week rehabilitation programme, 29 patients (73 per cent) did not complete the programme. Besides a lower education and lower income, patients who dropped out reported more irritability, anxiety, helplessness/hopelessness and alienation compared to patients who completed the programme (Shenkman, 1985). Although more research is needed in this area, it appears that psychosocial factors have an effect on attendance and drop-out during rehabilitation above and beyond the effect of pulmonary functioning {Fischer, 2007 470 /id}. Hence, apart from the aim of reducing psychological burden, behavioural scientists may positively influence drop-out rates by treating the underlying psychosocial factors.

KEY AREAS FOR FUTURE RESEARCH

This chapter has outlined some of the most important issues concerning Chronic Obstructive Pulmonary Disease and pulmonary rehabilitation. Though many areas have been covered extensively in the literature, some areas within pulmonary rehabilitation deserve further study. First of all, in terms of efficiency, the optimal duration of the programme and the desired intensity of the exercise need to be further examined. Second, future research has to demonstrate the benefits of interventions aimed to maintain the gains from rehabilitation (after-care programmes). Third, adherence and drop-out during pulmonary rehabilitation programmes need to be further investigated, in order to optimise the use of available resources and reduce chances of biased results in effectiveness studies. Fourth, most firm conclusions about the effects of rehabilitation can be drawn from meta-analyses. However, these analyses can only compare clinical trials that have used identical measurement instruments. A standardisation in the outcomes measures is therefore needed to perform such analyses. Fifth, the effect of different psychological interventions alongside a rehabilitation programme deserves further attention. Thus far, randomised controlled interventions with adequate power, investigating the relative benefits of single and combined intervention techniques have been scarce. Finally, there is a need for research on the benefits of comprehensive rehabilitation programmes for psychological and social well-being of patients with COPD. Since social performance and participation in everyday life are the ultimate goals of pulmonary rehabilitation, it is surprising how little there is known about the value of rehabilitation programmes in this domain.

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CHAPTER 3

Participation and drop-out in pulmonary rehabilitation: a qualitative analysis of the patients’ perspective

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ABSTRACT

Objective: To examine patients' pre-treatment beliefs and goals regarding pulmonary rehabilitation.

Design: Qualitative study using semi-structured interviews.

Setting: Interviews conducted at participants' homes.

Subjects: Twelve patients with chronic obstructive pulmonary disease who had been referred to a rehabilitation clinic.

Main measures: Patients' beliefs about pulmonary rehabilitation, self-set treatment goals and anticipated reasons for drop-out.

Results: Patients' beliefs about pulmonary rehabilitation comprised positive aspects (participation as an opportunity for improvement, a safe and multidisciplinary setting, presence of motivating and supporting patients) and negative aspects of exercising in a rehabilitation centre (e.g. disruption of normal routine, being tired after training, transportation difficulties, limited privacy and confrontation with severely ill patients). Four types of treatment goals were formulated: increase in functional performance, weight regulation, reduction of dyspnoea, and improvement of psychosocial well-being. Four clusters of anticipated reasons for drop-out were identified: the intensity of the programme, barriers to attending (e.g. transportation problems, sudden illness and other duties/responsibilities), lack of improvement, and social factors.

Four different attitudes towards pulmonary rehabilitation could be distinguished: optimistic, 'wait and see', sceptic, and pessimistic. Follow-up data revealed that whereas a pessimistic attitude (high disability, low self-confidence, many concerns) was related to decline, the 'sceptic' patients (many limitations in daily functioning, few treatment goals, few anticipated benefits, no involvement in referral, many concerns regarding pulmonary rehabilitation) had dropped out during the course.

Conclusions: Uptake and drop-out may be related to patients' perceived disabilities, expected benefits and concerns with regard to rehabilitation, practical barriers and confidence in their own capabilities.

Introduction

Although lung function in patients with chronic obstructive pulmonary disease (COPD) generally does not improve as a result of pulmonary rehabilitation, improvement in quality of life, functional performance, emotional well-being and a reduction in dyspnoea and fatigue have consistently been found.[1-3] Despite these positive results, a considerable proportion of the eligible patients decline participation or drop out during the programme.[4-9] Clearly, decline and drop-out prevents the patient from attaining optimal health benefits. Furthermore, high drop-out rates are problematic since they lead to inefficient use of available resources (rehabilitation staff, facilities) and pose a threat to the validity of effect studies. Despite the clinical and scientific relevance, the reasons for decline and drop-out in pulmonary rehabilitation (PR) have seldom been investigated systematically. Most studies on the causes of drop-out in pulmonary rehabilitation have focused on the role of disease characteristics and practical barriers [e.g.5,10] Although these causes are important, they are also difficult to manipulate.

Previous research has drawn attention to the role of patients' beliefs about illness and treatment in predicting uptake of and adherence to medical regimens.[11] In pulmonary and cardiac rehabilitation, patients' treatment beliefs have been found to play a role in uptake and adherence. [12,13] Treatment beliefs also have predicted both uptake and adherence in other areas of health behaviour, such as adherence to medication,[14,15] regular care seeking among patients with diabetes,[16] participation in a cancer support group, [17] or an asthma self-management programme.[18]

Other studies have focused on the role of treatment goals in relation to adherence and drop-out. It appears that whereas divergence between the individual's aims and the objectives of the programme leads to dissatisfaction and low adherence,[19] the incorporation of objectives that are personally valued by the patient and perceived as achievable is related to lower drop-out during exercise.[20] Since beliefs and goals are largely acquired by personal experience and interpersonal interaction, they may be amenable to intervention.[21,22]

Studies in other illnesses have demonstrated the role of patients' treatment beliefs, goals and practical barriers in predicting drop-out in rehabilitation. This pilot study set out to explore these factors in pulmonary rehabilitation. Since this is a relatively new field of research, a qualitative approach was deemed appropriate for uncovering the richness of individual views.

Methods

Recruitment

Research ethics approval was obtained before recruitment, which took place in collaboration with two rehabilitation centres in the Netherlands. Consecutive patients who had been referred for pulmonary rehabilitation and who were diagnosed with COPD were invited to participate. No restriction was made upon first or repeated participation in a rehabilitation course, stage of disease or sociodemographic characteristics.

Procedure

During the intake appointment with the pulmonologist at the rehabilitation centre, patients were informed about the study and asked to sign written consent to be approached. Patients who gave consent were called by the researcher (MF) and the goal and procedure of the study were explained. Appointments were scheduled to conduct semi-structured interviews at the patients' home in the weeks between intake and the formal start of the rehabilitation programme. Interviews lasted between 50 and 100 minutes. The interviews were audio taped and transcribed verbatim. After three months follow-up data were gathered about drop-out.

Interview

For the purpose of this study an interview protocol was developed and tested by the research team. The first part of the interview covered sociodemographic (e.g. age, marital status, profession, daily activities), medical (medical history, symptoms, functional limitations) and psychosocial topics (e.g. reaction to diagnosis, influence of disease on social activities, reactions of others to COPD). After discussing the reason for referral, patients were asked about their beliefs regarding the rehabilitation programme. When necessary, specific probes were used regarding programme content, pros and cons of training in a rehabilitation centre and being in a group with other patients.

With regard to goals, patients were asked what they hoped to achieve during the rehabilitation. Also, possible conflicting goals (valued activities patients would miss out on as a result of their rehabilitation) were discussed. Finally, patients were asked to think of circumstances that would make it difficult for them to complete the programme.

Analysis

In analysing the interviews an interpretative phenomenological analysis (IPA) approach was used.[23] This type of analysis aims to capture the meaning of a certain phenomenon by closely following the personal experience and perception of an event or object. At the same time, IPA acknowledges that researchers will interpret the accounts using their own theoretical background. By interpreting the verbal accounts, the IPA researcher will form an impression of the underlying cognitions.[24]

During the analysis, the researcher (MF) read the transcripts in search for themes. Similar themes were grouped and ordered hierarchically (key themes and subordinate themes). Because new codes and themes emerged during the analytical process, all interviews were coded twice. Another researcher (MS) independently coded the first two interviews to judge consistency of interpretation. The interpretations were compared and discussed.

Results

Participants

Four women and eight men with COPD were interviewed. Partners were present during five interviews. Mean age of the patients was 61 years. Two patients were still in employment. Six patients had stopped working because of their illness, four had retired. Except for three patients, all were married or were involved in an intimate relationship (Table 1).

Table 1. Patient characteristics.

Patient no.	Sex	Age	Prior rehabilitation	GOLD stage[a]
1	Male	75	No	II
2	Male	34	No	III
3	Male	59	Yes	II
4	Male	77	Yes	II
5	Female	54	Yes	IV
6	Male	74	No	III
7	Female	43	No	II
8	Male	77	Yes	III
9	Male	68	Yes	II
10	Male	59	No	II
11	Female	52	No	IV
12	Female	60	No	IV

a) Global Initiative for Chronic Obstructive Lung Disease (GOLD) classification of disease severity (I (mild), II (moderate), III (severe), IV (very severe)). [25]

Referral to rehabilitation

Patients said they had been referred because of progressive restrictions in daily functioning or complaints about shortness of breath. For three patients the reason for referral was the short time interval between consecutive hospital admissions. According to these patients, rehabilitation was intended to strengthen the body's resilience and resistance to illnesses. Three patients remembered the doctor telling them nothing could be done for them in hospital but that attending a rehabilitation programme might improve their condition. These patients regarded PR a last chance to improve their health status.

> *The lung specialist said: 'There's nothing I can do for you'. But he said that he had seen patients who were able to take on some activities after participating in a rehabilitation programme. 'Cos now I can walk up and down the street and that's it. Perhaps I'll be able to walk one block then. And that was the doctor's aim. They also told me: 'We can't cure you. But the intention is to get you some more [lung] volume.' (patient 8)*

Four out of seven newly referred patients had difficulty recalling the reasons for referral or stated that they were provided with no explanation at all.

> *No, there was no real reason for referral, because the x-rays were unchanged and my lung volume was the same. The oxygen in my blood had gone up so there was no real reason. But [the doctor] thought it might be beneficial. I did not ask why. (patient 1)*

One patient had asked for PR himself. He had been in rehabilitation before and was very positive about it. Moreover, fear resulting from worsening dyspnoea led him to search for alternative treatments. Being eventually referred was a great relief and the anticipation of being in PR reduced his feelings of anxiety.

Beliefs about pulmonary rehabilitation

Anticipated benefits of participation in a pulmonary rehabilitation programme

Patients talked about several aspects in the programme that appealed to them. Obviously, the programme was seen as an opportunity for improvement. Furthermore, the rehabilitation centre was thought of as a safe environment in which they could exercise. The idea of being watched over was reassuring. The multidisciplinary character of the rehabilitation was mentioned as positive by reattending patients.

> *See, the good thing is you're being supervised when you're busy. And then they suddenly say: 'You'd better see the speech therapist'. And that's nice. It's one integrated system. All these people are watching you. (patient 9)*

Recognition by staff members was regarded an important feature of the rehabilitation programme. Five patients felt uneasy to discuss their illness with others unfamiliar with COPD.

> *I noticed it during the intake consultation and when talking to the nurse: they quickly understand what you mean. Of course, they deal with that everyday. Every story, every excuse, they must have heard for at least 80 times. So there's no need for decorum, withholding things. They'll know. There's no point in trying to deceive them. (patient 11)*

The social aspect of exercising together with other patients was anticipated as being enjoyable by both newly referred patients and reattending patients. Patients thought they could 'learn' from each other. For male patients 'learning from others' meant understanding how to do the exercises. Women rather wanted to learn how others coped with their illness. Being in a group of individuals experiencing the same illness provided an opportunity to receive and provide emotional support, as was expressed by patients who had been in prior rehabilitation. This seemed particularly important for patients who experienced difficulties in explaining to others what Chronic Obstructive Pulmonary Disease was about. They were often confronted with misunderstanding and stigma such as being anorectic or rheumatic when using a wheelchair. Besides being supportive, fellow patients were thought to be motivating and encouraging.

Concerns about participation in a pulmonary rehabilitation programme

Besides the benefits of rehabilitation, patients also expressed concerns regarding their participation in pulmonary rehabilitation. One common theme was the interference of the programme with other activities or routines. Five patients stated that they would miss valued social activities.

> *I always say to my friends: "I'll be back in the summer and then we'll have a good time together". So I thought I'd be training three days a week and the other days I'd be completely worn out. My summer would be lost. So, at first I decided not to participate. But last time, I went to the beach. It was such a disappointment. And I thought: something needs to happen if I want to be able to do something next year. And that's when I decided to go. (patient 5)*

Patients indicated they had to develop a way to adjust their daily routine and find a new balance between the demands of the rehabilitation programme and those of ordinary life. Especially for patients who lived alone, this meant they had to plan ahead when to buy the groceries, do the household chores or cook. Work had to be postponed until after the programme but for these patients this appeared to have no negative financial consequences. Nearly all patients were able to put these concerns into perspective. As long as the programme would produce results and serve valued goals, patients were willing to give up these activities.

> *Even if you have to give up those things…you have to make choices. Do you want to grab a cup of coffee with someone or do you want to work on your health? (patient 2)*

Besides having to give up valued activities, training in a rehabilitation centre was associated with other negative aspects. Patients were concerned about the journey to the rehabilitation centre. For one patient travelling was the most burdensome element of rehabilitation. Another patient, who described himself as a homebody, was uncomfortable with the idea of being away from home for such a long time, even if it was in his own interest. One patient who had asked for rehabilitation himself mentioned the finite character of the programme being the most important downside to rehabilitation.

> *And when you have to leave, that's what scares you. That you're a bit lost. I felt that the last time, when I was discharged from hospital: now I have to do it alone. I have to take care of myself again. (patient 9)*

Two patients disliked the idea of the conversations with a social worker or psychologist. They would rather keep their problems to themselves. Furthermore, they became tired of telling the same story over and over again. Finally, the anticipation of being completely worn out at the end of each training session was regarded as a serious concern.

Although generally considered positive, eight patients also had concerns about training with other patients. They worried about the limited privacy, confrontation with severely ill patients or motivation of other participants.

> *Well, some are only there for the fun instead of to get better. That's not what it's meant for, of course. It can be a nuisance when they're chattering for 5 or 10 minutes, sitting on a fitness machine, while in the mean time you could have used it. But you don't wanna send them away, of course. (patient 3)*

Anticipated reasons for drop-out

All patients could think of at least one possible reason for drop-out, although patients varied in the time needed to think of one. Anticipated reasons for drop-out can be divided into four categories. The most often cited reason was the intensity of the programme. Five patients expressed their concern that if the intensity of the programme would exceed their capabilities, they would not be able to continue.

> *The only reason I can think of is when I'm worn out when I come home. If it lasts… and you are exhausted for the whole evening and the next morning. That's not what it's supposed to be like. Sure, it can happen the first week, you can expect that. But not that you are too tired to eat after training. (patient 8)*

The second cluster of causes for drop-out comprised several barriers to attending the rehabilitation classes. Transportation difficulties were an example of this category. Patients who lived alone, had no car of their own, who were unable to drive due to their illness and who didn't want to ask others to drive indicated that completing the programme would be difficult if no alternatives (e.g. lending a car, sharing transport with other patients in the programme or being financially compensated by health care insurance) would become available. Another cited reason for not being able to attend was being suddenly taken ill (e.g. flu or pneumonia). A third barrier to attend and subsequently drop-out were patients' other duties or responsibilities, such as (return to) work, care for an ill spouse or family member and lack of help in looking after pets.

A third cause for drop-out was related to treatment outcome (mentioned by three patients without prior experience in rehabilitation). These patients indicated they would stop if they were not able to notice any improvements.

> *Look, if I didn't notice any improvement – I mean, after three weeks you can't tell- but when I'm halfway through the programme and I can't feel no difference, I would be wasting my time. (patient 7)*

Finally, a fourth cluster consisted of psychosocial factors as cause for drop-out. Homesickness, unsupportive remarks by staff or patients and conflict with other patients were examples of this category.

Self-set treatment goals

We asked what patients wished to achieve in rehabilitation. Ten patients mentioned one or more goals. Two patients did not formulate any goals. A total of nineteen goals were cited, which could be headed under four categories; strength and condition, weight, dyspnoea, and psychosocial well-being. Improvement of physical condition, increase in muscle strength and the resulting improvement of functional performance were cited by eight patients as goal for the rehabilitation. Achievement of these goals would permit the respondents to maintain their normal life and avoid becoming more and more dependent on others.

> *Patient: For instance taking a shower. You become more dependent when it comes to dressing and undressing. And your socks. 'Cos I can't bend over. And your shoes… my wife has to do that for me.*
> *Partner: So what? It doesn't matter!*
> *Patient: It does! I hate that idea. There are more and more things she has given up for me. And that's why I want to dress myself again. And take a shower. I'm sure I will be able to do that again. (patient 9)*

A second category consisted of weight related goals. Four patients aimed to lose some kilos and three patients wanted to gain weight. Weight loss was mentioned by patients who also aimed to increase their physical condition. Weight gain was thought to be associated with an increase in energy level, muscle mass or resistance to illnesses.

A third category comprised dyspnoea related goals. Two patients stated their goal was to get 'some more air' but had no idea how this should be achieved. Two other patients wanted to improve their breathing techniques since they both thought they had acquired a poor breathing technique.

> *I want to learn to breathe better. 'Cos that's a problem too. I have a poor breathing technique. It runs in the family. That's why I often become short of breath and hyperventilate. That's something I'd like to learn. (patient 12)*

Finally, psychosocial goals were mentioned. Patients hoped that the counselling by a social worker or psychologist might help them to regain a positive outlook, reduce stress, or accept a life that is characterized by a decrease in social support, functional limitations and unexpected setbacks.

> *When you feel terrible every four weeks and it lasts for two or three weeks, that's hard. You can't plan ahead anymore. And when you start to recover, it always goes downhill again. So I hope my resistance to illnesses will improve during the rehabilitation and that I will be able to do more and can accept that at other times I can do less. (patient 3)*

Attitudes towards participation

After reading and comparing the twelve interviews, four attitudes towards participation in pulmonary rehabilitation were distinguished (see Figure 1): optimistic, 'wait and see', sceptic, and pessimistic. Two researchers independently assigned the 12 respondents to one of the four groups. In ten cases there was a match between the raters. In the other two cases agreement was reached after discussion.

Optimistic patients were convinced of the need to attend the rehabilitation programme (because of serious limitations in their daily and social activities). They had positive expectations of the health benefits. At the same time they were aware of the possible negative consequences of participation. A 'wait and see' attitude was adopted by two patients who were referred for the first time, had relatively few restrictions in their daily functioning and were consequently not sure about whether the programme would result in improvement of their health status. Although these patients were able to formulate treatment goals, the need for improvements appeared rather low compared with the other patients. Two patients were sceptic about their referral. They shared the experience of not having been involved in the decision to refer them for rehabilitation. Furthermore, they mentioned many adverse consequences of participation (mainly a disruption of normal routine) and were not convinced that their participation would lead to improvements in their health. They were able to formulate only a few treatment goals (e.g. 'get more air').

Finally, one patient was pessimistic and decided to decline participation after the physician had told him that the programme would be 'intensive'. He had interpreted this as a signal that the programme would be too strenuous for him. Furthermore, transportation difficulties (cost and time), dislike of group participation and the lack of expected benefits had contributed to his decision. He also expected to be hurried by the training staff. He disliked this idea since he had become used to reducing the speed of his daily activities over the years.

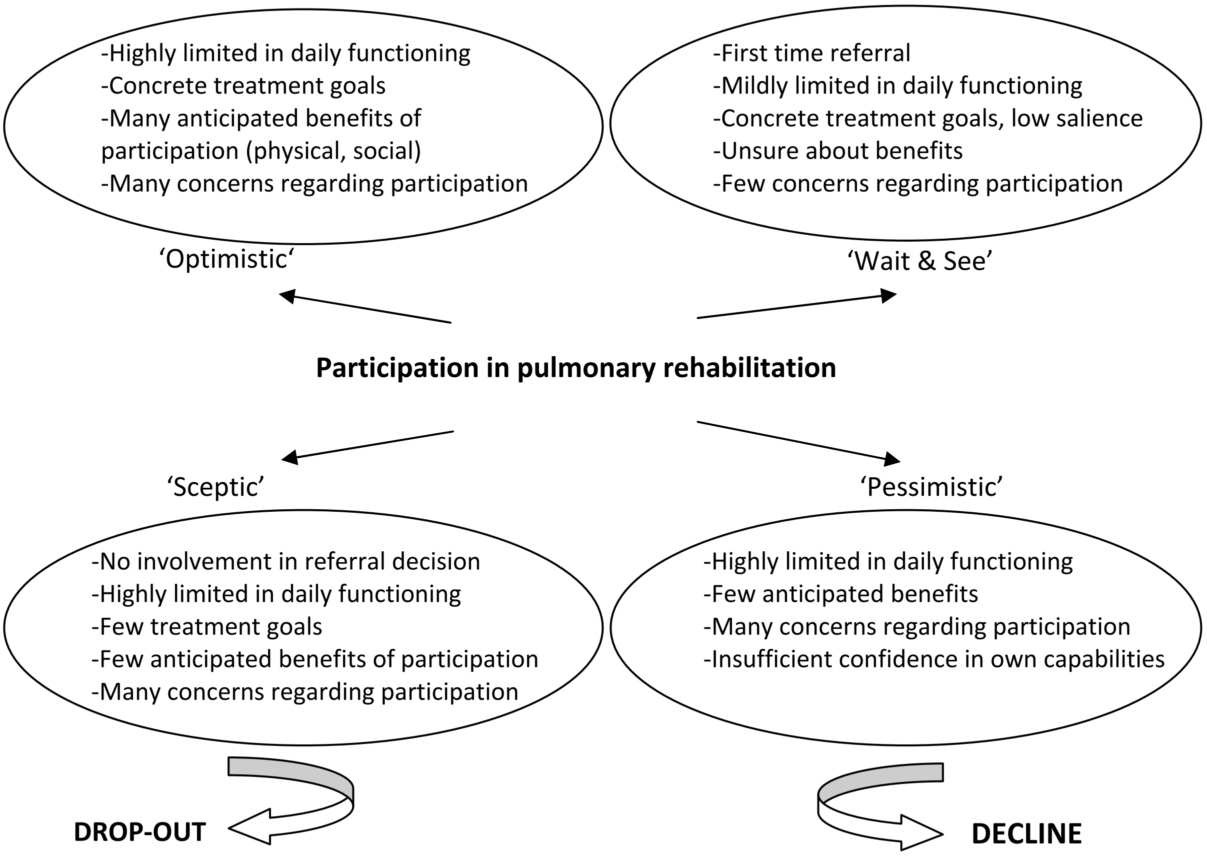

Figure 1. Attitudes of referred patients with COPD towards participation in a pulmonary rehabilitation programme.

<u>Follow-up data</u>

In the weeks following the interviews, patients' attendance at the rehabilitation clinic was monitored to see if possible drop-out could be related to one of these four attitudes. Eleven patients attended rehabilitation. Two of them dropped out (both before the third week of the course). These two patients were the only patients who had been judged as 'sceptic' towards participation in rehabilitation.

Discussion

This study has focused on patients' pre-treatment beliefs and goals with regard to participation in pulmonary rehabilitation as well as anticipated reasons for drop-out. The qualitative method we have adopted for this study does not allow us to make statistical generalizations. Since our sample was small and heterogeneous our findings deserve further quantitative research (currently in progress). Purposive sampling with more stringent inclusion criteria would have added to the reliability of our results. On the other hand, most rehabilitation groups consist of patients with and without prior experience in rehabilitation. Therefore, the diversity within our study sample may more realistically reflect patients' expectations and experiences one may encounter in a clinical setting.

A second limitation pertains to researcher reflexivity. Although two researchers have judged patients' attitude towards pulmonary rehabilitation independently, we cannot rule out the possibility that our theoretical preconceptions have coloured the interpretation of the data.

Notwithstanding these limitations, our results have led us to believe a few key factors might be related to patients' uptake and drop-out during pulmonary rehabilitation. An important factor may be the perceived burden of the disease. For patients who experience few symptoms or restrictions in social participation referral may come too soon. Patients in this study who had a 'wait and see' attitude were only mildly restricted in their daily functioning and were not sure why they had been referred. According to theory, patients need to experience a significant threat to their health and must be convinced that treatment is needed in order to start searching for a solution.[26] Research has shown that uptake and adherence are higher when patients perceive their illness as more severe, and experience greater discomfort.[27,28]

Second, along with others we believe that patients need to be convinced their illness is manageable [29,30] and that attending rehabilitation is an effective method in finding relief of their complaints.[31,32] In this light it would be recommended to avoid presenting rehabilitation as a 'last hope' as this may be regarded by patients as a signal that healthcare providers are sceptic about the possible benefits of attending PR. In fact, strength of referral has been found to be one of the most powerful determinants of patients' participation in rehabilitation.[12,33]

Third, concerns about participation have a negative effect on patients' participation in rehabilitation.[13] Optimistic as well as sceptic and declining patients had concerns about participation, but only the optimistic patients were able to put these into perspective and let the anticipated benefits prevail.

A further prerequisite for participation seems to be the patient's belief that he or she is able to perform the activities which are part of rehabilitation such as travelling and exercising. Patients' belief in their own capabilities has been demonstrated to be important in the initiation and relapse of exercise behaviour. [34,35] In our study the patient declining participation was the only one who was convinced that travelling and exercising would overtax his resources.

At this point we cannot distinguish the factors that are responsible for uptake from those responsible for completing pulmonary rehabilitation. Adherence with a medical regimen can be considered as a way of coping with an illness as it is perceived.[36] In line with others we believe that perceptions of illness and treatment together with contextual factors such as barriers and self-efficacy influence the choice of health behaviour (e.g. participation in pulmonary rehabilitation) and the continuation is dependent on an evaluation of that behaviour.[11] The individual and contextual factors which direct the onset of health behaviour also play a role in its (dis-)continuation. For instance, whereas low confidence in the benefits of treatment may lead to decline, disappointment resulting from too overly optimistic expectations may lead to drop-out. [37,38] In the same way specific barriers may hinder uptake of rehabilitation but may also influence drop-out later on.[37,39]

We feel that in order to judge and reduce the risk of drop-out, patients' beliefs regarding rehabilitation should be explicitly discussed during the intake phase. By doing this, misconceptions about the rehabilitation can be dispelled and the delivery of care can subsequently be tailored to the needs of the patient and his or her social system. [40] Furthermore, drop-out levels may be reduced by setting achievable treatment goals in collaboration with patients which enables them to become actively involved in their own care and more committed to the programme.[41,42]

Conclusion

Although pulmonary rehabilitation has been demonstrated to lead to improvements in physical and psychosocial well-being, participation requires much effort, persistence, and flexibility from patients. Uptake and drop-out appear to be a continuous trade-off between the subjective need for improvement, the anticipation of attainable benefits and confidence in one's own capabilities on the one hand, and concerns and barriers to attending classes on the other.
Clinical messages:

- Chronic Obstructive Pulmonary Disease patients' beliefs about their illness and treatment appear to play a role in uptake and drop-out of pulmonary rehabilitation.
- Patients' anticipated reasons for drop-out include the intensity of the programme, barriers to attending, lack of experienced improvement and social problems (e.g. interpersonal conflicts, homesickness).

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CHAPTER 4

Drop-out and attendance in pulmonary rehabilitation: the role of clinical and psychosocial variables

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ABSTRACT

Background: In spite of the well-demonstrated benefits for patients with COPD, pulmonary rehabilitation programmes show considerable drop-out and suboptimal attendance rates. The purpose of this prospective study is to examine causes for drop-out and non-attendance during a 12-week multidisciplinary pulmonary rehabilitation programme, and to investigate whether sociodemographic and medical factors as well as patients' perception of their illness are related to drop-out and non-attendance.

Methods: Two hundred and seventeen patients with COPD who were referred to a rehabilitation centre participated in this multicentre study. Prior to treatment, patients received a questionnaire which included the Illness Perception Questionnaire-Revised. Clinical data were drawn from medical records. Drop-out and attendance were recorded during the programme.

Results: Fifty patients (23%) did not complete the rehabilitation course, of which half was due to medical reasons (e.g. exacerbations, hospitalisations). Non-completion could not be predicted by baseline sociodemographic, clinical or psychological variables. Patients who declined treatment did not differ from patients who dropped out due to medical reasons. On average, patients attended 92% of all scheduled appointments. Of all missed appointments, approximately 20% were accountable to factors beyond patients' control (e.g. absent therapists, hospitalisations). Smoking, living alone, a lower fat free mass and lower confidence in treatment increased the chance of patients not attending an appointment during rehabilitation.

Conclusion: In general, adherence in rehabilitation is high. However, paying attention to patients' nutritional status and creating a positive expectation of treatment during referral and intake appear to be important if one aims to optimise patients' attendance during rehabilitation.

INTRODUCTION

Multidisciplinary pulmonary rehabilitation programmes have become an important non-pharmacological treatment modality for patients with chronic obstructive pulmonary disease (COPD),(1) with beneficial effects on exercise tolerance, fat free mass, quality of life and perceived fatigue and dyspnea.(1;2) Unfortunately, a considerable proportion of the eligible patients does not complete the rehabilitation programme. Studies with larger study samples (N>100) and a minimum duration of seven weeks show that non-completion rates usually vary between twenty to forty percent, (3-6) although non-completion rates of over 70% have also been reported.(7) Attendance rates during rehabilitation have seldom been reported but appear to vary around 90% for intensive short-term programmes (<12 weeks) with three training sessions a week. (8-10)

High drop-out and non-attendance rates lead to ineffective use of training staff and equipment. Whereas drop-out or non-participation prevent patients from experiencing the potential benefits of rehabilitation, poor attendance is associated with less favourable outcomes of treatment.(11;12) Although drop-out and non-attendance may in some cases be unavoidable (e.g. hospitalisation, transportation difficulties), they can also result from a deliberate decision. According to Leventhal's Common Sense Model,(13) individuals have acquired lay theories about health and illness. These illness schemata, which consist of underlying specific illness cognitions (e.g. the controllability of the illness), guide the individual's actions in order to cope with the health threat. As such, it is not the objective disease characteristics but rather the perception of the illness that results in a specific action. Using their common sense, patients will adhere to a certain treatment only if they consider it a sensible thing to do (i.e. expected to be effective in diminishing the threat to one's health). Interpretation, coping efforts and evaluation of the effectiveness of these efforts can be considered as a cyclical process of self-regulation. Recently, we detailed the contribution of illness perceptions to outcomes in COPD-patients.(14)

The purpose of this prospective study is to investigate drop-out and attendance rates during rehabilitation programmes for patients with COPD and to provide an overview of reasons for drop-out and non-attendance. A second aim of this study is to investigate whether patients' illness perceptions add to the prediction of drop-out and non-attendance after controlling for sociodemographic and medical variables.

METHODS AND MATERIALS

Procedure

Between November 2005 and November 2007, all consecutive patients diagnosed with COPD who had been referred to a centre for pulmonary rehabilitation (Rehabilitation Centre Breda (RCB), Sint

Franciscus Gasthuis (SFG), Rijnland Rehabilitation Centre (RRC)) were invited to participate in this study. Patients who consented were contacted before the start of the rehabilitation. Participating patients received a questionnaire and were requested to return it before the start of the rehabilitation. After being informed, patients were asked to give written permission to obtain information from their medical files. Patients who had already started rehabilitation or had primary lung conditions other than COPD were excluded from the study. Patients who stopped attending appointments before the end of the formal rehabilitation programme and who missed the functional follow-up tests were regarded as non-completers. Attendance was derived by comparing patients' weekly appointment schedules with the daily work logs of the individual therapists. Reasons for non-completion and non-attendance were extracted from work logs and patients' medical files. The study was approved by the LUMC and SFG ethics committees and subsequently by the boards of the rehabilitation centres.

Rehabilitation programme

All programmes had a duration of 12 weeks. The rehabilitation programme consisted of supervised exercises (strength and endurance training, activities of daily living (ADL) training), relaxation training, breathing exercises and group education. Additional counselling was tailored to the individual patient's needs and included support by a psychologist or social worker, nutritional interventions, occupational therapy, speech therapy and smoking cessation counselling. All rehabilitation centres offered an outpatient programme of three days a week. In Breda an intensive programme of five days a week (outpatient or inpatient) was also available.

Baseline assessment

Participants were asked to fill out a questionnaire which included sociodemographic questions (age, sex, education, relational status, smoking status and pack years) and the Illness Perception Questionnaire-Revised (IPQ-R),(15) a validated and reliable instrument used to assess patients' representations of illness which has been used previously in respiratory research.(16;17) The questionnaire comprises eight subscales: identity (the number and type of symptoms patients associate with their illness), timeline acute/chronic (how long patients think their illness will last), timeline cyclical (whether patients think their condition is always present or is cyclical), consequences (perceived consequences for patients and their social network), illness coherence (the degree to which patients feel they understand the condition), emotional representations (the emotional response to the illness), personal control (how much control patients perceive they have over the illness and symptoms) and treatment control (the strength of belief that the treatment is effective in controlling the disease).

Baseline pulmonary function tests included postbronchodilator expiratory flow rates (FEV_1 and FEV_1%pred), and Vital Capacity (VC, VC%pred). A classification of disease severity (GOLD stage) was made according to international guidelines.(18) A maximum exercise test was performed with a cycle ergometer following the ERS/ATS recommendations.(19) A field exercise test was performed by means of the six minute walking test. Dyspnoea and perceived exertion (Borg CR10) were assessed after the walk test.(20) Patients' weight, body mass index (BMI) and fat free mass index (FFMI) give an indication of the systemic effects of the disease. The Medical Research Council (MRC) dyspnoea scale was used to assess patients' level of breathlessness during daily activities.(21)

Statistical analyses

Descriptive statistics (frequencies, mean and standard deviation) are used to present patients' background and medical characteristics, drop-out and attendance rates, as well as reasons for drop-out and non-attendance. T-tests, Chi-square tests, and analyses of variance are applied to study differences between subgroups of patients. Kruskal-Wallis was used where assumptions for parametric tests had been violated. Using hierarchical logistic regression analyses with forced entry it was tested whether illness perceptions added to the prediction of drop-out and high versus poor attendance after entering sociodemographic and clinical variables which showed at least borderline univariate association with the outcome variable ($p<0.1$).

RESULTS

A total of 331 patients gave permission to be contacted by the researcher. Of these, 263 patients (79%) who had not started their treatment agreed to participate in this study and received a questionnaire. Medical charts showed that nine patients had a diagnosis other than COPD (e.g. lung cancer, cystic fibrosis). Of the 254 remaining patients, 217 (85%) returned the questionnaire. There were no significant differences between patients who returned the questionnaire and those who did not in sex, age, baseline lung function (FEV_1, VC, saturation in rest), exercise tolerance (6MWD, Borg scores, Watt max & VO2max) and body composition (BMI, FFMI). Our study population consisted of slightly more men (56% vs. 44%, see also Table 1). Most patients had a partner (76%) and had stopped working (82%). Most patients were ex-smokers (self-report). There was a large variation in pack years ranging from 3 to 126 years. Nearly 40% of the patients suffered from severe COPD (stage III, GOLD international classification of disease severity). On average, patients walked 378 meters in six minutes (range 250-648m).

Table 1. Baseline characteristics of study sample (N=217).

	Mean	(SD)	N	%
Age	63.4	(9.4)		
Sex				
Female			95	44%
Male			122	56%
Education				
Elementary school			54	25.4%
Lower vocational training			97	45.5%
Secondary educational training			45	21.1%
Higher vocational training or university			17	8.0%
Relational status				
Partner			163	75.5%
Single			53	24.5%
Working status				
Active			39	18.1%
Retired			176	81.9%
Smoking status				
Never smoker			18	8.4%
Stopped smoking			167	77.7%
Infrequent smoker			12	5.6%
Daily smoker			18	8.4%
GOLD stage				
I			17	8.0%
II			61	28.6%
III			82	38.5%
IV			53	24.9%
FEV$_{1\ (l)}$	1.27	(0.64)		
FEV$_1$ % pred.	46.0%	(20.7)		
SaO2 rest %	94.7%	(2.4)		
VO2 max $_{(ml/min)}$	1102	(360.5)		
VO2 % pred	64.7%	(21.2)		
Watt max	62.2	(34.7)		
Watt % pred	46.2%	(22.4)		
6MWD $_{(m)}$	378	(117.0)		
Borg exertion Post 6MWD	4.3	(2.3)		
Borg dyspnoea Post 6MWD	4.8	(2.1)		
BMI $_{(kg/m^2)}$	27.8	(5.5)		
FFMI $_{(kg/m^2)}$	16.9	(2.7)		
Pack years	39.8	(22.9)		

FEV$_1$: forced expiratory volume in one second; FEV$_1$ % pred: percentage of predicted FEV$_1$; VC: vital capacity; VC % pred: percentage of predicted VC; SaO2 rest %: oxygen saturation; VO2 max: maximal oxygen uptake; VO2 max % pred: percentage of predicted VO2 max; Watt max: max work load (cycle ergometer): Watt max % pred: percentage of predicted Watt max; 6MWD: 6 minute walk distance: BMI: Body Mass Index; FFMI: Fat Free Mass Index

Drop-out

One hundred and sixty-seven patients (77%) completed the rehabilitation course, with no significant difference across the rehabilitation sites (76-81%). Causes for non-completion were: exclusion during the clinical assessment in the rehabilitation centres (n=14), drop-out due to medical reasons (n=24), and patients declining rehabilitation (n=12).

Exclusion of patients by the rehabilitation centre occurred when patients were perceived to be insufficiently motivated, had physical or psychosocial contraindications (n=11)) or were expected to have little chance of improvement (e.g. patients demonstrated adequate coping with their illness (n=3).

Medical drop-out was frequently due to COPD-related causes, mainly exacerbations (n=15). Non-COPD causes for drop-out were cardiac infarction (n=2), neuromuscular problems (n=3), eye surgery (n=1) and tumours (n=2). One patient had died during the rehabilitation period.

Patients who decided they would not commence or continue in rehabilitation did so mainly because of other activities which they did not want to give up (e.g. part-time job, hobbies (n=3)) or dissatisfaction with aspects of the programme organisation (e.g. having to share a bedroom with another patient, inconvenient appointment times (n=4)). Other reasons for decline such as homesickness, relocation or financial difficulties were mentioned only occasionally.

Patients who completed the rehabilitation course did not differ from non-completers with respect to sociodemographic or clinical variables (data not shown). There was a trend towards a higher education (p=0.06) and lower MRC score (p=0.09) among those who completed the course. Non-completers had no different perceptions of their illness than patients who completed the programme (F (9, 193) = 1.08, p>0.1). A logistic regression analysis predicting non-completion with education and MRC dyspnoea as independent variables did not significantly predict drop-out.

Within the group of non-completers, there were also no differences in the abovementioned sociodemographic and clinical variables between patients who were excluded, patients who declined or those who dropped out due to medical reasons (all univariate ANOVA's / Kruskal-Wallis p>0.05). Patients who declined rehabilitation also did not have different perceptions of their illness than patients who dropped out or those who were excluded (F (18, 72) = 1.48, p>0.1).

Attendance

Attendance data could be retrieved from 161 of the 167 completers. Patients who completed the course attended on average 114 appointments during their rehabilitation programme. Eighty-eight of these appointments were exercise related. Only 14 patients (9%) attended all appointments. Overall, 91.9% of all scheduled appointments were attended (range 61-100%).

Many causes are responsible for patients' non-attendance during scheduled appointments (Figure 1). A little over 20% of missed appointments were due to causes that were beyond patients' control (white bars in Figure 1). When patients cancelled an appointment or did not show up, COPD-related complaints (e.g. dyspnoea, exacerbations) were the most frequently reported causes for non-attendance (Figure 1). Non-COPD medical reasons (e.g. muscle aches) accounted for 9% of absenteeism. Other activities (e.g. birthday, holiday) and attending a funeral or taking care of an ill family member were responsible for non-attendance in 9% and 5%, respectively. Some exercises performed in a therapeutic swimming pool were not attended when patients were afraid of water or could not swim. Only seldom (2%) did patients not show up because they chose to skip a single appointment scheduled on a day (e.g. one educational meeting) or left early during the training day because they had to wait too long between appointments.

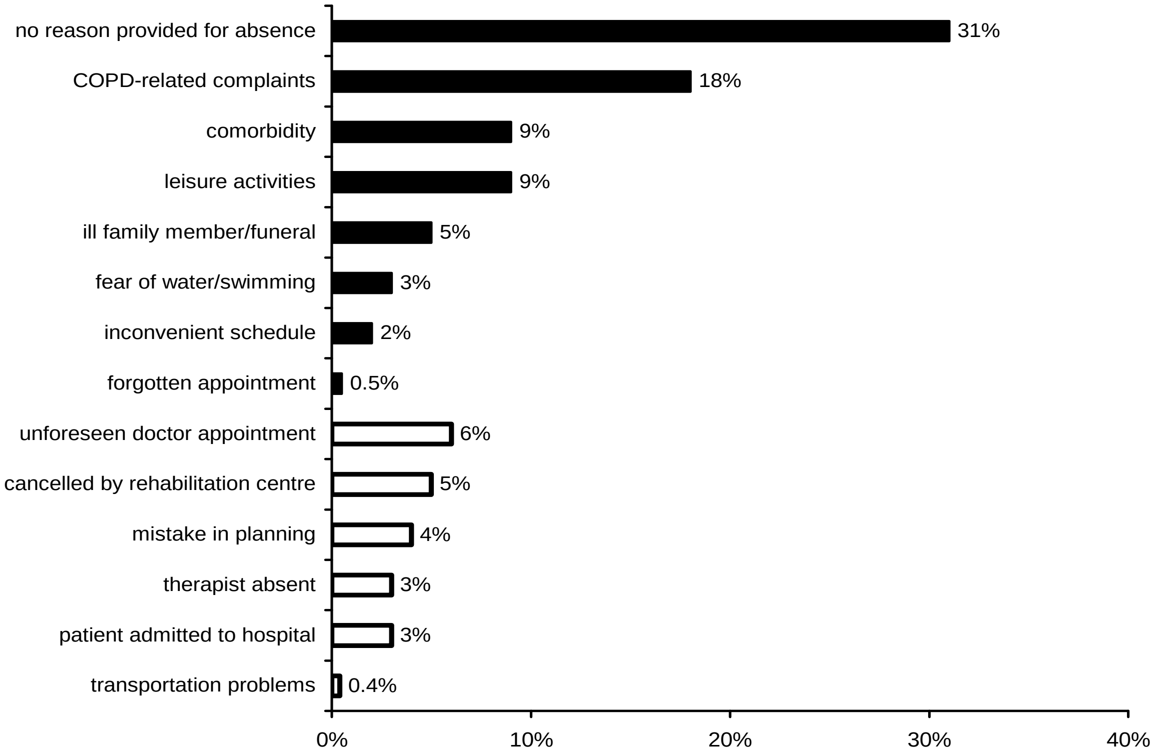

Figure 1. Causes for missed appointments

With the aim of constructing a measure of patient attendance, the number of appointments cancelled by patients (not including uncontrollable absenteeism represented by the white bars in Figure 1) was divided by the number of appointments patients did attend. Twenty patients had a ratio of zero (indicating they had not cancelled any appointment themselves). The maximum value for this ratio was 0.46 (approximately one in every three appointments cancelled by the patient). To examine differences between 'high' and 'poor' attenders, two groups were created based on a median split (ratio non-attendance/attendance 1:20), resulting in two groups with equal sample size (n=79 vs. n=80). Patients in the high attendance group had a higher BMI (28.1 vs. 26.3 kg/m^2, respectively) and a higher FFMI (17.6 vs. 16.5 kg/m^2, respectively) than patients in the poor attendance group (Table 2). Furthermore, in the poor attendance group there were more females, current smokers and patients living without a partner.

Table 2. Characteristics of high versus poor attendance group (t-test).

	High attendance (n=79)	Min-max	Poor attendance (n=80)	Min-max	p-value
Sex					
Female	37%		50%		
Male	63%		50%		.09#
Age	64.3		61.9		.10
Education (range 1-5)	2.19	1-5	1.96	1-5	.13
Living with partner	82%		66%		.02#
Current smoker	7.8%		16.5%		.06#
Pack years	38.4	4-126	42.9	3-113	.26
Travel distance (km)*	13.9	1-75	10.8	1-45	.20
Travel time (min)*	24	5-60	21	5-60	.20
FEV$_1$ (litres)	1.30	0.51-3.07	1.24	0.43-3.09	.47
FEV$_1$ % pred	47.1%	20%-88%	44.8	12%-98%	.44
6MWD (meters)	378	108-575	389	119-612	.53
BMI (kg/m^2)	28.1	18.9-52.3	26.3	13.1-41.5	.04
FFMI (kg/m^2)	17.6	11.6-33.6	16.5	11.8-23.7	.01
MRC dyspnoea (range 1-5)	3.36	1-5	3.24	1-5	.54

#Chi^2-test; *Outpatients only. FEV$_1$: forced expiratory volume in one second; FEV$_1$ % pred: percentage of predicted FEV$_1$; 6MWD: 6 minute walk distance; BMI: Body Mass Index; FFMI: Fat Free Mass Index

The poor and high attendance group differed in their illness perceptions (MANOVA F (8, 142) = 2.47, $p<0.05$) (Table 3). Eight patients had incomplete data on one or more of the IPQ-subscales, which explains the lower number of patients in Table 3, as compared to Table 2. Univariate analysis showed that patients who missed more appointments had less confidence in the effectiveness of their treatment (F (1, 149) = 4.54, $p<0.05$)). Patients' treatment control perceptions were not related to FFMI, sex, marital status or smoking status. Female patients had a lower FFMI (but not BMI) than men (16.4 vs. 17.4 kg/m^2, $p<0.05$).

Table 3. Differences in illness perceptions between high adherent and poor adherent group.

	'High' attendance (n=78)	'Poor' attendance (n=73)	P-value
Identity (range 0-15)	5.2	5.7	.27
Consequences (range 6-30)	21.0	20.7	.67
Timeline chronic (range 6-30)	26.5	26.6	.89
Timeline cyclical (range 4-20)	12.9	13.3	.49
Illness coherence (range 5-25)	17.2	18.1	.18
Emotional representations (range 6-30)	15.4	14.3	.19
Personal control (range 6-30)	18.9	19.3	.56
Treatment control (range 5-25)	16.3	15.4	.04

MANOVA F (8, 142) = 2.47, p=0.015

To study the relative relationship of independent factors on patients' attendance (which was positively skewed), a hierarchical logistic regression analysis was deemed appropriate. The analysis showed that FFMI is an important predictor of non-attendance (Table 4) (BMI was not entered in the regression analysis due to its high correlation (r=0.87) with FFMI). The treatment control subscale of the IPQ-R, which was entered in the last step of the regression analysis, added to the prediction of non-attendance.

Table 4. Hierarchical logistic regression analysis predicting poor attendance during pulmonary rehabilitation.

	Variables	Odds ratio	95% C.I.	p-value	Correct prediction	Significance of step
Block 1	Living with partner	.54	.24-1.20	.13	62.1%	p=0.052
	Stopped smoking	.49	.17-1.42	.19		
	Male sex	.70	.34-1.43	.33		
Block 2	Living with partner	.56	.25-1.28	.17	64.1%	p=0.033
	Stopped smoking	.65	.22-1.92	.43		
	Male sex	.75	.36-1.57	.45		
	Fat free mass index	.87	.76-1.0	.05		
Block 3	Living with partner	.56	.25-1.29	.18	66.0%	p=0.023
	Stopped smoking	.63	.21-1.90	.41		
	Male sex	.75	.36-1.58	.45		
	Fat free mass index	.87	.76-1.0	.04		
	IPQ Treatment control	.87	.76-.99	.03		

Final model Chi^2 =17.4, p<0.01.

DISCUSSION

The present study showed that patients' adherence to a pulmonary rehabilitation programme is high. More than 75% of the referred patients who participated in this study completed the rehabilitation course. Patients who completed the programme attended on average more than 90% of all scheduled appointments. Non-completion and non-attendance were often attributable to medical causes. Where the patient decided not to start or continue the rehabilitation programme, reasons were often practical (e.g. time constraints) or related to dissatisfaction with the organisation of care. Drop-out or decline was not related to medical and psychosocial variables. Patients' attendance however, was related to their fat free mass and their perception of effectiveness of the treatment.

Whereas the percentage of patients who drop out due to medical reasons is similar to other multidisciplinary rehabilitation programmes finding drop-out rates varying from 0-11%, the proportion of respondents declining rehabilitation appears to be lower than in other studies (9-37%).(4;22;23) The obtained attendance rate in our study appears to confirm findings by others. (8-10) General parameters of disease severity did not differentiate between completers and non-completers. We also did not find differences between patients who declined rehabilitation, patients who dropped out due to medical reasons and patients who were excluded by the rehabilitation centre. These results are consistent with other studies (24-26) and suggest that functional performance and pulmonary functioning play only a modest role in predicting patients' drop-out during rehabilitation.

With regard to attendance during rehabilitation, female patients, patients who lived alone and current smokers were more inclined to cancel an appointment. Sex, marital status and smoking status have mainly been investigated in relation to drop-out but apparently they also appear to be related to patients' attendance. Most studies support our finding that smokers and patients who live alone are likely to be less adherent in rehabilitation.(4;5;10;26;27). However, in contrast to our findings, Emery and colleagues found that males were less adherent than females.(28)

The results from our regression analysis showed that patients' belief in the effectiveness of treatment and their fat free mass index were the strongest predictors of attendance. Whereas perceived treatment effectiveness has previously been demonstrated to be a strong predictor of patients' adherence behaviour in rehabilitation, (29-31) the relation between FFMI and attendance, to the best of our knowledge, has not been previously investigated. Sabit and coworkers have found an association between BMI and attendance but did not investigate patients' FFMI.(10) However, FFMI may more accurately express disease severity than BMI,(32) and two explanations can be presented for the relationship between FFMI and attendance. First, lower FFMI is associated with worse functional performance (6MWD, MRC dyspnoea, handgrip strength), decreasing chances of patients to comply with the training schedule.(32;33) Furthermore, in muscle-wasted patients maximal and submaximal exercise are related to a heightened systemic inflammatory reaction. Because these inflammations may be a predictor of exacerbations, a decline in fat free mass can lead to an increase in exacerbation frequency, negatively influencing patients' attendance.(34-36) The lower average FFMI in women may also explain the spurious relation between sex and attendance.

This study is one of the few that have focused on causes and predictors of drop-out and non-attendance from a biopsychosocial perspective. The present study has been conducted in three rehabilitation centres which increases the generalisability of our findings. However, we have to acknowledge that self-selection may have caused a bias in our sample. We cannot rule out the possibility that patients who agree to participate in a scientific study also have a tendency towards socially desirable behaviour, leading to greater adherence during treatment. Furthermore, the subgroups of patients who decline rehabilitation or drop-out due to medical reasons may have been too small for us to discover significant differences among the subgroups of non-completers.

Smoking cessation counselling and nutritional interventions are integrated into comprehensive rehabilitation programmes. Although there are no indications that smokers profit less than non-smokers from pulmonary rehabilitation,(1) our data support Young and colleagues' statement that: "nonadherence with a rehabilitation programme may be a reflection of nonadherence with other management strategies".(26) Interventions to assist patients in refraining from smoking are not only beneficial for patients' pulmonary functioning but may also increase the cost-effectiveness of the rehabilitation.(37) In similar fashion, nutritional interventions for muscle wasted patients during pulmonary rehabilitation can produce a desirable by-effect. Some studies have shown an increase in patients' fat free mass using nutritional supplementation during rehabilitation.(38;39) Studying the effects of nutritional interventions on patients' attendance during pulmonary rehabilitation may therefore be a fruitful area for future investigation.

Finally, the results of this study demonstrated a relationship between attendance during rehabilitation and patients' perceptions about the effectiveness of treatment. These perceptions are influenced by the patient-provider interaction,(29;40) which suggest that communication between patient and healthcare provider may profit from an exploration and discussion of patients' illness and treatment perceptions during the referral or intake phase. Although on average patients demonstrate high attendance, creating a positive yet realistic expectation of the rehabilitation appears to be an important objective if one aims to optimise patients' adherence during rehabilitation.(41)

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CHAPTER 5

The dynamics of illness perceptions: testing assumptions of Leventhal's Common Sense Model in a pulmonary rehabilitation setting

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ABSTRACT

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

Conclusions: We conclude that, in accordance with Leventhal's Common Sense Model, 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.

Background

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, Scharloo, Kaptein, Thong, Boeschoten, Grootendorst *et al.*, 2009; Griva, Jayasena, Davenport, Harrison, & Newman, 2009; Hagger & Orbell, 2003; Scharloo, Kaptein, Schlösser, Pouwels, Bel, Rabe *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 character of human self-regulation. Although longitudinal observational studies suggest that patients’ views about their condition appear to be relatively stable (Foster, Bishop, Thomas, Main, Horne, Weinman *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 organisation 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, Benjamin, Brownlee, Diefenbach, Leventhal, Patrick-Miller *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, & Kincey, 2006). In patients with diabetes, Lawson and colleagues have showed that emotional representations decrease within two years after the diagnosis whereas illness coherence increases (Lawson, Bundy, & Harvey, 2008). In a six year longitudinal study of patients with osteoarthritis, Bijsterbosch and colleagues found that whereas the dimensions timeline chronic and illness coherence had increased, patients reported a reduced perception of personal control over their illness and emotional reaction to their disease (Bijsterbosch, Scharloo, Visser, Watt, Meulenbelt, Huizinga *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 Common Sense Model it is assumed that 'representations are shaped and reshaped by the success or failure of specific 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 1600 patients with back pain (Foster et al., 2008). As a group, no change was observed in patients' illness perceptions over the course of 6 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, characterised 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, Bauldoff, Carlin, Casaburi, Emery, Mahler *et al.*, 2007).

Investigating illness perceptions in this group of patients allows us to test the following two hypotheses: A) 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. B) 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, Black, Cotton, Kennedy, Wilson, & Sutton, 2009; Scherer, Schmieder, & Shimmel, 1998). We expect no association 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 (RCB), Sint Franciscus Gasthuis Rotterdam (SFG), Rijnland Rehabilitation Centre Leiden (RRC)) 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 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, ten (9%) could not be contacted at follow-up and seven (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 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 (ADL) 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 outpatient programme (three days a week). In Breda an intensive programme of (five 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 sociodemographic questions (age, sex, education, marital status, year of diagnosis, smoking status and pack years) and the Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 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, Scharloo, Fischer, Snoei, Cameron, Sont *et al.*, 2008).

During the assessment phase in the rehabilitation centre, baseline pulmonary function tests included postbronchodilator expiratory flow rates (FEV_1 and percentage of predicted value of FEV_1 (FEV_1%pred)), and Vital Capacity (VC & 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 six-minute walk test (6MWT) (Palange, Ward, Carlsen, Casaburi, Gallagher, Gosselink *et al.*, 2007). Dyspnoea and perceived exertion (Borg CR10) were assessed after the walk test (Borg, 1982). Patients' weight, body mass index (BMI) and fat free mass index (FFMI) 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 (5 items), Fatigue (4 items), Emotional functioning (7 items) and Mastery (4 items). All questions are answered on a 7-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 (FEV_1%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' sociodemographic 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 Value in 1 second (FEV_1%pred)), exercise tolerance (Six Minute Walk Distance, 6MWD) and Body Mass Index (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. 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 smoking before the start of the rehabilitation programme. Sixty percent 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 second).

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)	1.33	(0.64)		
FEV_1%pred	47%	(20%)		
SaO2 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)		

FEV_1: forced expiratory volume in one second; FEV_1%pred: percentage of predicted FEV_1; SaO2 rest%: oxygen saturation at rest; 6MWD: 6-minute walk distance; CRQ: Chronic Respiratory Questionnaire.

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, $p<0.001$)). 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

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

*p<0.05, **p<0.01, ***p<0.001

FEV$_1$%pred: percentage of predicted Forced Expiratory Volume in 1 second; 6MWD: 6 minute walk distance with greater perceived consequences (r=.31, p=0.007) and stronger chronic timeline perceptions (r=.33, p=0.003) (See Table 2). Perceptions of personal control were inversely related to time since diagnosis (r=-.40, p<0.001). 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=0.098). 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 five years or more ago (N=43) differed from perceptions of patients who had been diagnosed within the past four years (N=37) after controlling for differences in clinical variables (MANCOVA F(8, 68)=4.10, p<0.001). Univariate tests indicated that patients who were diagnosed five 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 Value in 1 second (FEV_1%pred)), six minute walk distance, and Body Mass Index 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=0.41).

Outcomes of pulmonary rehabilitation

Paired samples t-tests showed that rehabilitation was effective in increasing patients' walk distance from 381 to 415 metres (t (72)= -3.61, p=0.001), while decreasing Borg dyspnoea scores after the walk test from 5.1 to 4.6 (t (68)= 1.99, p=0.05). Post treatment Borg fatigue scores however, were not significantly lower than at baseline. Patients' BMI had remained unchanged at 27.5 kg/m^2.

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=0.027) and a decrease in Borg dyspnoea scores after the walk test (r=-.39, p=0.004). Goal accomplishment was also related to a decrease in Borg fatigue scores, although this association did not reach statistical significance (r=-.22, p=0.12). 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

Table 3. Illness perceptions at baseline of patients diagnosed less than five years ago (N=37) and patients diagnosed five 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)	.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)	.02	.87
Emotional representation	5-25	.90	14.9 (5.0)	14.5 (4.7)	.34	.56

domains of Dyspnoea (r=.41, p=0.002), Fatigue (r=.53, p<0.001) and Mastery (r=.34, p=0.014) but not for the domain Emotional Functioning (r=.20, p=0.151).

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.

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=0.02) and emotional representations (r=-.25, p=0.04) 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 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<0.05, **p<0.01

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<0.05, **p<0.01, ***p<0.001

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 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.

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

Illness Perceptions T2	Step	Independent variables	ΔR^2	Adj. R^2	ΔF	B
Identity	1	Identity T1	30%	28%	23.06***	.52***
	2	Years since diagnosis	2%	28%	1.18	.12
	3	Goal achievement	1%	28%	.89	-.11
Consequences	1	Consequences T1	37%	36%	36.35***	.58***
	2	Years since diagnosis	0%	35%	.00	-.01
	3	Goal achievement	7%	40%	5.81*	-.26**
Timeline chronic	1	Timeline chronic T1	33%	31%	25.27***	.66***
	2	Years since diagnosis	5%	35%	3.88#	-.24#
	3	Goal achievement	0%	34%	.14	-.04
Timeline cyclical	1	Timeline cyclical T1	26%	24%	18.24***	.46***
	2	Years since diagnosis	0%	23%	.00	.02
	3	Goal achievement	7%	29%	5.38*	.27*
Personal control	1	Personal control T1	26%	25%	18.11***	.28***
	2	Years since diagnosis	9%	33%	7.23*	-.35**
	3	Goal achievement	9%	41%	7.66**	.31**
Treatment control	1	Treatment control T1	25%	23%	18.14***	.50***
	2	Years since diagnosis	0%	22%	.00	.03
	3	Goal achievement	3%	24%	2.00	.17
Illness coherence	1	Illness coherence T1	17%	17%	10.90***	.41***
	2	Years since diagnosis	0%	17%	.13	.05
	3	Goal achievement	0%	17%	.19	.06
Emotional representation	1	Em. representation T1	44%	43%	42.73***	.65***
	2	Years since diagnosis	0%	42%	.42	-.08
	3	Goal achievement	2%	43%	1.67	-.13

#p<0.07, *p<0.05, **p<0.01, ***p<0.001

DISCUSSION

In support of Leventhal’s Common Sense Model, 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, Scharloo, Abbink, van't Hul, van Ranst, Rudolphus *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 Common Sense Model 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 five 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, Tálamo, Halbert, Perez-Padilla, Lopez, Muiño *et al.,* 2009; Franciosi, Page, Celli, Cazzola, Walker, Danhof *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 Common Sense Model, 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, emphasise the cyclical character 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 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, de Jongste, Otten, Koëter, Wempe, Ranchor *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=0.004)). 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 the goal–setting process. 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 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 illness, despite otherwise optimal medical care (Nici, Donner, Wouters, Zuwallack, Ambrosino, Bourbeau *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, Carey, Cradock, Daly, Davies, Doherty *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 positive 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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CHAPTER 6

Concerns about exercise are related to walk test results in pulmonary rehabilitation for patients with COPD

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ABSTRACT

Background: Although international guidelines on pulmonary rehabilitation acknowledge that psychological factors contribute to exercise intolerance in patients with Chronic Obstructive Pulmonary Disease (COPD), the few empirical studies investigating this association have found inconsistent results.

Objective: To investigate whether negative affect and beliefs about exercise of patients with COPD would be related to baseline six-minute walk (6MW) test results in a pulmonary rehabilitation setting, after correction for physical variables (sex, age, height, weight and lung function). A second aim was to examine whether patients' beliefs are associated with treatment outcomes, as measured by an improvement in 6MW distance.

Method: A 12-week pulmonary rehabilitation program was completed by 166 patients. Beliefs (perceived necessity and concerns) about exercise and negative affect were assessed by a questionnaire. Clinical data were obtained from medical records.

Results: Baseline 6MW distance was positively related to younger age, male gender, better pulmonary function and having fewer concerns about exercise. After rehabilitation, patients had increased their walk distance by 12% (32 meters), on average. Baseline physiological and psychological variables were unrelated to patients' response to treatment (increase in walk distance). However, subgroup analysis showed that for patients with mild to moderate airflow obstruction, concerns about exercise were negatively related to response to treatment.

Conclusion: We conclude that patients' beliefs about the negative consequences of exercise are associated with baseline 6MW test performance and response to treatment for patients with mild to moderate COPD. We recommend that patients' concerns about exercise are discussed and, if necessary, corrected during the intake phase.

International guidelines on pulmonary rehabilitation state that, apart from pathophysiological mechanisms, psychological processes are likely to influence exercise intolerance in patients with chronic respiratory conditions (1). However, the few empirical studies that have investigated this assumption to date have been inconsistent in their conclusions. Borak and coworkers have concluded that "exercise tolerance in COPD is not affected by abnormalities in emotional status" (2). In a later study, Trappenburg and colleagues concluded that the outcome of pulmonary rehabilitation is independent of patients' baseline psychological and sociodemographic characteristics (3). By contrast, more recent studies by Cully (4) and Giardino (5) found a significant negative association between general anxiety and exercise test results, calling for further investigation into the role of negative affect in exercise tolerance.

In addition to the impact of patients' affect on behavior, leading behavioral theories emphasize the role of individual's beliefs regarding a particular object, event or action that shape a person's motivation to perform a certain behavior (6;7). Within the context of health behavior the Necessity-Concerns framework (8) was developed to explain how patients' beliefs about treatment influence treatment adherence. As an extension to Leventhal's Common Sense Model of self-regulation (9;10) the central assumption of this framework is that the motivation to comply with a certain treatment regimen depends on the perceived necessity (potential benefits) of this particular treatment and specific concerns (costs or risks) patients may have about the proposed treatment. Additionally, by influencing adherence to medical protocols, patients' beliefs about treatment are likely to be related to health outcomes (11). Previous studies have found evidence for the assumed influence of patients' treatment beliefs on patients' compliance with treatment regimens (12-18) and treatment outcomes in physical therapy programs (19-21).

As physical exercise is an important predictor of physical condition in patients with Chronic Obstructive Pulmonary Disease (COPD) and serves as the cornerstone of pulmonary rehabilitation programs (1;22;23), investigating how patients' beliefs about exercise are related to baseline exercise tolerance and treatment outcomes after rehabilitation is relevant for the interpretation of exercise test results and holds potential value for patient education.

The aim of this study is to test the hypothesis that patients' beliefs about exercise are related to baseline walk test results, after correcting for the influence of physical variables and general negative affect. Following assumptions of the Necessity-Concerns framework, patients' motivation to engage and persist in strenuous exercise during a pulmonary rehabilitation program is likely to be higher with increased perceived necessity of engaging in this exercise program, whereas it is expected to be lower when patients have serious concerns about the negative effects of treatment. Since models of health behavior have greater explanatory power as their contents become more specific to the behavior in question (24;25), it is expected that specific beliefs about the exercise program are more closely related to exercise performance than general negative affect.

A second aim is to investigate whether patients' treatment beliefs are related to response to treatment (increase in walk distance). We expect the relationship of treatment beliefs and treatment outcomes in particular for those patients with mild to moderate airway obstruction, who are less likely to be limited by physiological complications and comorbidity associated with advancing disease, and hence may have a greater potential to train at higher intensity (26). The 6-minute walk (6MW) test was chosen as outcome variable as it is one of the most widely used field tests for the assessment of patients' exercise tolerance and an important indicator of response to treatment (1;27;28). Age, gender, weight and height have been found to be the most important independent predictors of the 6-minute walk distance in healthy subjects (29;30). These four variables will serve as control variables in the analyses together with the degree of airway obstruction (percentage of predicted Forced Expiratory Volume in 1 second (FEV_1%pred)), which has been found to be a significant predictor of walk test results in a healthy elderly population and in patients with COPD (2;27;31-33) and is considered as the principle indicator of disease severity in COPD (34).

METHODS

Procedure

This study was part of a larger study on drop-out and non attendance in pulmonary rehabilitation programs. Patients who had been referred to one of three centers for pulmonary rehabilitation (Rijnland Rehabilitation Center (RRC), Rehabilitation Center Breda (RCB), Sint Franciscus Gasthuis (SFG)) were invited to participate in this study during the intake phase. All patients provided written informed consent and gave the researchers permission to obtain sociodemographic and clinical data from their medical files. Patients who participated received a questionnaire and were requested to return it before the start of the rehabilitation program. Patients who had already started rehabilitation or had primary lung conditions other than COPD were excluded from the study. The study was approved by the SFG and Leiden University Medical Center (LUMC) ethics committees and the boards of the three rehabilitation centers.

Rehabilitation program

Rehabilitation programs were organized following ATS/ERS guidelines for pulmonary rehabilitation (1). The program was 12 weeks in duration and consisted of supervised exercises (strength and endurance training of the lower and upper limbs, recreational sports and activities of daily living), relaxation training and breathing exercises. Group education focused on several aspects of disease management such as inhalation technique, nutrition and coping with the social and psychological consequences of living with COPD. As comprehensive rehabilitation programs are tailored to the needs of the individual patient, optional treatment modalities consisted of counseling by a psychologist or social worker, nutritional interventions, occupational therapy and smoking cessation counseling. All rehabilitation centers offered an outpatient program of three days a week. In RCB an intensive program of five days a week was also available.

Baseline assessment

Before entering the rehabilitation program, participants filled out a questionnaire which included sociodemographic questions, negative affect and patients' perceived necessity and concerns regarding exercise. Negative affect was assessed by means of the Hospital Anxiety and Depression Scale (35), a reliable and valid instrument measuring anxiety and depression (7 items for each subscale) on a 4-point scale. Perceived necessity and concerns were assessed on two Likert-type 7-point scales (See Appendix 1). The items were originally designed and validated for use in cardiac rehabilitation research (13) and slightly modified to be suitable for use in an elderly COPD population (e.g. "resume my activities" instead of "return to work"). Scores for the Necessity and Concerns subscales are represented as the mean of the individual items. Both scales showed acceptable internal consistency in the present study (Cronbach's α=.68 (Necessity) and α=.65 (Concerns)).

Baseline pulmonary function tests included postbronchodilator forced expiratory flow rates and vital capacity according to recommended standards (36). A classification of disease severity (GOLD stage I-IV) was made according to international guidelines (37). Higher GOLD stages represent worse lung function. Patients' body mass index (BMI) and fat free mass index (FFMI) were assessed during the intake and provide an indication of the systemic effects of the disease.

The 6MW test was used to assess patients' functional exercise performance. During the 6MW test subjects are asked, with standardized encouragement, to cover as much distance as possible. Distance walked and Borg scores, measuring patients' fatigue and dyspnea (38) were recorded after the walk test. A percentage of predicted walk distance was calculated by dividing patients' distance walked by predicted walk distance (with correction for sex, age, height, and weight). Troosters et al's formulas were used to calculate patients' predicted walk distances (30). The 6MW test was performed before the start of the formal program and again at the end of the rehabilitation program.

Statistical analyses

Descriptive statistics (frequency, mean and standard deviation) were used to present patients' sociodemographic and medical characteristics. T-tests and correlation analyses were performed to investigate the associations between sociodemographic and medical characteristics and patients' treatment beliefs. Linear hierarchical regression analysis with forced entry was performed to establish the relationship between clinical variables, negative affect and patients' treatment beliefs with baseline 6MW distance (in meters). Gender, age, weight and height were entered in the first model. Airway obstruction (forced expiratory volume in first second of expiration, expressed as percentage of predicted value (FEV_1%pred)) was added in the second model. Anxiety and depression (HADS) symptoms were added in the third model. The final model included gender, age, weight, height, FEV_1%pred, negative affect and patients' necessity beliefs and concerns regarding the exercise program.

With regard to treatment response, differences in walk distance are expressed as percentage of the pre-treatment value (39). Investigation of this variable showed that it had a non-normal distribution (Kolmogorov-Smirnov Z=1.85, p=.002). In order to facilitate the interpretation of results, it was decided to dichotomize this variable for further analyses. An increase in distance walked of 10% or more relative to baseline is generally accepted as a minimal important difference (MID) (40), and is considered as an indication of treatment response. Therefore this degree of improvement was chosen as a cut-off point to create two subgroups: those who achieved the MID of 10% or more increase in 6MW and those who did not achieve this MID. Multivariate analysis of variance (MANOVA) was performed to explore whether patients who improved their walk distance with 10% or more differed from those who had not achieved the MID in sociodemographic and clinical variables, negative affect or treatment beliefs.

To test our hypothesis that the association of patients' treatment beliefs and treatment response depends on patients' degree of airway obstruction we conducted a moderation analysis following steps outlined by Frazier et al. (41). In a hierarchical logistic regression model the main effects of FEV_1%pred and treatment beliefs on treatment outcome (percentage increase in walk distance) were entered in the first step. In the second step the interaction terms (the product of centered variables) of airway obstruction and treatment beliefs were entered.

RESULTS

Two hundred and seventeen patients entered the rehabilitation program of which one hundred and sixty-six (77%) completed the program. Data on drop-out are reported elsewhere (42). No differences were found in patients' treatment beliefs between drop-outs and patients who completed the rehabilitation. Differences in medical or sociodemographic variables at baseline between drop-outs and completers were also not significant (42).

Baseline characteristics of those patients who completed the rehabilitation program are presented in Table 1. Sixty-three percent of the patients were classified as having severe or very severe COPD (FEV_1% ≤50% of predicted value). No differences in baseline 6-min walk distances were observed between patients who entered a compact program and patients who entered an intensive program (390 meters vs. 369 meters, respectively; t=1.22, p=.22). The percentage of predicted walk distance was also approximately similar (76% vs. 72%, respectively; t=.93, p=.35).

Table 1. Patient characteristics at baseline (N=166).

	Mean	SD
Sex (N, %)		
Female	75	45%
Male	91	55%
Age	63.0	9.4
Height (cm)	169	10.0
Weight (kg)	77.5	17.6
Body Mass Index (kg/m^2)	27.0	5.8
Fat Free Mass Index (kg/m^2)	16.9	2.8
FEV_1 (l)	1.27	0.6
FEV_1 (%pred)	46%	19.2
GOLD stage (N, %)		
I	13	8%
II	49	30%
III	66	40%
IV	38	23%
VC (l)	3.38	1.0
VC (%pred)	95.5%	20.0
SaO2 rest %	94.6%	2.5
6MWD (m)	381	111.0
6MWD (%pred)	74%	21.9
Borg fatigue, post 6MWD	4.4	2.3
Borg dyspnea, post 6MWD	4.8	2.1
HADS Anxiety	7.3	4.8
HADS Depression	7.6	3.8
Treatment necessity	5.4	1.1
Treatment concerns	2.9	1.4

FEV_1: forced expiratory volume in one second; VC: vital capacity; SaO2: arterial blood oxygen saturation at rest; 6MWD: 6 minute walk distance, 6MWD (%pred): percentage of predicted 6 minute walk distance; HADS: Hospital Anxiety and Depression Scale.

Women and men held comparable views regarding treatment necessity (t= -.58, p=.57) and concerns about treatment (t= -.42, p=.68). Correlation analyses revealed that associations between patients' treatment beliefs and age, height, weight and pulmonary function were also non-significant (see Table 2**)**. Perceived necessity and concerns showed a negligible negative relationship (r= -.08, p=.32).

Table 2. Association of treatment beliefs with sociodemographic and clinical variables and negative affect. Values are presented as Pearson r scores unless stated otherwise.

	Necessity	p	Concerns	p
Sex (mean score)				
males	5.4		2.9	
females	5.5	.57#	3.0	.68#
Age	-.09	.25	-.05	.57
Weight	.04	.59	-.12	.11
Height	-.12	.12	-.11	.17
FEV_1%pred	-.04	.58	.02	.83
HADS Anxiety	.08	.30	.22	.004
HADS Depression	-.06	.45	.24	.002

t-test. FEV_1: forced expiratory volume in one second; HADS: Hospital Anxiety and Depression Scale.

Association of treatment beliefs and baseline walk test performance

Results from the hierarchical regression analysis showed that in the first model (with gender, age, weight and height as predictors), age showed a highly significant relationship with walk distance (Table 3). In the second model, FEV_1%pred was the most important predictor of walk distance. Age remained a significant predictor of walk distance. After correction for differences in lung function males performed somewhat better than females on the 6MW test (difference approximately 40 meters) although this did not reach statistical significance (t=-1.74, p=.08). In the third model anxiety and depression were added. These variables were unrelated to baseline 6MW distance. In the final model patients' exercise beliefs were added. This analysis showed that patients' concerns about exercising were negatively related baseline to walk test results after controlling for patients' clinical variables and negative affect. Perceived necessity of treatment was not related to baseline walk test results.

Table 3. Predictors of baseline six-minute walk distance (N=153).

	Predictors				Model fit		
		B	Beta	p	R^2	F	P
Model 1	Sex[#]	-29.00	-.13	.24	.057	2.23	.07
	Age	-2.83	-.24	.01			
	Weight	-.06	-.01	.92			
	Height	22.59	.02	.87			
Model 2	Sex	-40.47	-.18	.08	.175	6.22	<.001
	Age	-2.71	-.23	.01			
	Weight	-.77	-.12	.16			
	Height	78.33	.07	.54			
	FEV_1%pred	2.11	.36	<.001			
Model 3	Sex	-40.35	-.18	.09	.175	4.38	<.001
	Age	-.70	-.23	.01			
	Weight	-.77	-.12	.16			
	Height	78.74	.07	.54			
	FEV_1%pred	2.12	.36	<.001			
	HADS Anxiety	-.02	-.00	.99			
	HADS Depression	.10	.00	.97			
Model 4	Sex	-42.38	-.19	.08	.204	4.08	<.001
	Age	-2.66	-.22	.01			
	Weight	-.95	-.15	.09			
	Height	75.56	.06	.56			
	FEV_1%pred	2.23	.38	<.001			
	HADS Anxiety	.10	.00	.97			
	HADS Depression	1.36	.05	.66			
	Necessity	4.77	.05	.54			
	Concerns	-13.46	-.17	.03			

FEV_1: forced expiratory volume in one second: HADS: Hospital Anxiety and Depression Scale.
[#]Sex was coded 1= male 2= female.

Improvement in 6MW distance

Of the 166 patients who completed the rehabilitation program, 139 patients (84%) underwent a post-treatment 6MW test. Exacerbations in the final weeks before the end of the rehabilitation program and patients not showing up were responsible for incomplete follow-up data. No differences in baseline distance walked were observed between patients who underwent a post-treatment 6MW test and those who did not (380m and 392m, respectively (t=.44, p=.66).

On average, patients had increased their walk distance with 12% (median = +10%, range = -45%, +217%). Absolute walk distance had increased with 32 meters, on average (median = +35m, range = -197m, +258m). No differences in percentage change were found between patients who completed a compact rehabilitation program and patients who had completed the intensive program (Mann-Whitney U = 2314.5, p=.70)

No significant differences were found between patients who improved their walking distance by at least 10% (n=70) and those who had less than 10% increase in distance walked (n=69) with regard to age, weight, height, lung function, symptoms of anxiety and depression or beliefs about treatment (MANOVA F (8, 126) =.35, p=.94. See also Table 4 for univariate comparisons). All variables proved non-significant contributors to the explanation of variance in 6MW improvement (hierarchical logistic regression analysis; data not shown).

Table 4. Univariate comparison of sociodemographic and clinical characteristics, negative affect and treatment beliefs between patients with more and patients with less than 10% increase in walk distance. Values are presented as mean (SD).

	Patients with <10% increase in 6MWD (N=67)	Patients with ≥10% increase in 6MWD (N=68)	p
Age	63.8 (8.9)	63.6 (9.3)	.90
Weight	76.0 (16.5)	78.6 (18.5)	.39
Height	1.7 (0.1)	1.7 (0.1)	.78
FEV_1%pred	43.8 (18.4)	48.2 (19.2)	.18
HADS Anxiety	7.4 (5.2)	6.9 (4.7)	.55
HADS Depression	7.7 (3.9)	7.2 (3.9)	.46
Treatment necessity	5.5 (1.2)	5.5 (1.1)	.86
Treatment concerns	2.9 (1.5)	2.8 (1.5)	.91

FEV_1: forced expiratory volume in one second; HADS: Hospital Anxiety and Depression Scale.

Next, it was investigated whether the relation of treatment beliefs with change in walk distance would depend on the severity of patients' airflow obstruction. This moderation analysis demonstrated there was a significant interaction effect of airway function and patients' concerns about exercise on improvement in walk distance (see Table 5).

Table 5. Predictors of improvement in 6MWD (N=137).

	Predictors	Odds Ratio	Wald	p	Nagelkerke R^2	Model Chi^2	p
Model 1	FEV_1%pred	1.01	1.36	.24	2%	1.6	.67
	Necessity	.95	.10	.75			
	Concerns	.98	.02	.88			
Model 2	FEV_1%pred	1.01	1.58	.21	10%	10.5	.06
	Necessity	.91	.30	.58			
	Concerns	.95	.17	.68			
	FEV_1%pred x Necessity	.98	3.02	.08			
	FEV_1%pred x Concerns	.98	5.44	.02			

FEV_1: forced expiratory volume in one second

To explore the direction of the interaction effect two subgroups were created based on patients' lung function (FEV_1>50% (GOLD I/II) and FEV_1≤50% (GOLD III/IV)). Patients' concerns were recoded into a low and high concerns group based on a median split. For patients with mild to moderate airway obstruction (GOLD I/II), higher concerns about exercise were negatively related to increase in walk distance (Figure 1). Whereas 73% of the patients with no or minor concerns had increased their walk distance with at least 10%, this proportion was only 44% among those with many concerns (Chi^2 = 4.43, p=.04). By contrast, among patients with (very) severe airway obstruction the proportion of patients who had substantially improved their walk distance was smaller in the group with fewer concerns about exercise than in the group of patients who were more concerned (39% vs. 52%, respectively). This difference however was not significant (Chi^2 = 1.65. p=.20).

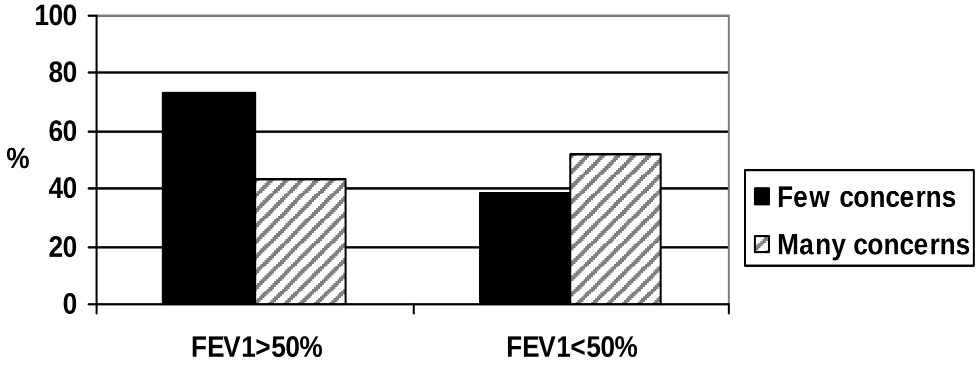

Figure 1. Percentage of patients with more than 10% increase in 6MW distance

DISCUSSION

This study has demonstrated that after correcting for the influence of physical variables, COPD patients' concerns about exercising in a rehabilitation program are related to the outcomes of the baseline 6MW test and patients' improvement in walk distance after completing a pulmonary rehabilitation program. Results showed that concerns about exercise had a modest but significant negative impact on patients' baseline test results. It was also demonstrated that for patients with mild to moderate airflow obstruction, having many concerns about the negative effects of exercise negatively influenced response to treatment (an improvement of walk distance by 10% or more (40)). ZuWallack and colleagues have suggested that patients with better lung function may have a greater potential to train at higher intensity, but that some patients may be 'underachievers' (26). Our data support this hypothesis by showing that for patients with mild to moderate airflow obstruction, the term 'underachievers' might represent those individuals with serious concerns about physical exercise.

In patients with severe airflow obstruction, the proportion of patients achieving the MID of 10% in walk distance was approximately similar for patients with minor concerns and patients with major concerns about the rehabilitation program. Although not reaching significance, it is interesting to note that patients with minor concerns about the exercise program less frequently achieved the MID in walk distance than patients who were more concerned (39% vs. 52% respectively), which seems counterintuitive. A possible explanation for this result is that patients with (very) severe COPD who are not concerned about physical exertion at all, may also show an inefficient adaptation to the limitations of their disease. Therefore, treatment objectives for patients with severe COPD who have no or little reservations concerning exercising are likely to aim at teaching patients disease management techniques such as energy conservation, pacing, planning and prioritizing, rather than at increasing patients' walk distance (43).

Contrary to our hypothesis we did not find any association of patients' perceived necessity of treatment with the outcomes of the baseline 6MWT or response to treatment. This result may be partly explained by the fact that most patients had high necessity scores (70% of the patients had a necessity score of 5 or higher on a 7-point scale). This may result in decreased power of the statistical tests. Additionally, the content of the concerns items appears to be more closely related to the exercise component within the rehabilitation program than the necessity items and may therefore exert a stronger influence on patients' exercise behavior.

Previous studies have obtained inconsistent results with regard to the relationship between indices of negative affect and exercise tolerance and response to treatment in patients with COPD (2-5). One explanation for the lack of association in the studies by Borak (1998) and Trappenburg (2005) might have been the rather small patient samples in those studies (49 and 65 patients, respectively). However, also in the present study with a larger patient sample negative affect and baseline exercise tolerance or response to exercise training were unrelated. Our findings and those of Borak and Trappenburg suggest that global indices of anxiety and depression, such as the HADS are less well suited to capture the specific affective processes involved in COPD patients' exercise behavior. In a preliminary additional examination of our data it was found that patients with more concerns about exercise were also more emotionally affected by their disease (as measured with a disease specific measure: the Illness Perception Questionnaire-Revised (44)), suggesting that affective processes are indeed involved. Therefore, future investigations into the role of affective processes involved in exercise intolerance of patients with COPD, should include measures that assess fears that are specifically related to exercise (e.g. using an adapted version of the Tampa Scale for Kinesiophobia (45) and affective reactions to physical sensations (e.g. Anxiety Sensitivity Index (46)) which are likely to occur during exertion.

Some limitations to this study must be acknowledged. Firstly, apart from Forced Expiratory Volume no other parameters of lung function were included in the analyses. Forced Expiratory Volume was included since it is currently the most important parameter of disease severity in COPD. Furthermore, it has been demonstrated to be related to walk test results (2;27;32;33), but appeared unrelated to the improvement in walk distance after an exercise program (26;39;47;48). Future studies with an extended set of physiological parameters (e.g. Inspiratory capacity/total lung capacity, muscle strength, comorbidities) are required to further investigate how cognitions and emotions influence patients' exercise tolerance and response to treatment after correction for these physical parameters.

A second limitation pertains to the internal consistency of the necessity and concerns subscale. It is possible that both scales refer to multiple underlying constructs. For instance, the necessity scale includes items about goal clarity ("I have a clear picture of what I want to achieve by attending pulmonary rehabilitation") and outcome expectations ("My physical condition will improve considerably if I attend the rehabilitation program for 12 weeks"). In a similar manner the concerns scale includes items on patients' expectations about the outcomes of exercising ("Some aspects of the rehabilitation program may be harmful to me") and their beliefs about their confidence (self-efficacy) to comply with the treatment protocol ("I may not be physically fit enough to participate in the rehabilitation program"). Both types of beliefs (outcome expectancies and self-efficacy beliefs) are relevant for patients' exercise behavior in a rehabilitation setting (49-51). Therefore, further studies should employ separate measures for outcome expectancies and self-efficacy expectations with regard to exercise to explore which type of beliefs are more closely related to patients' behavior.

A further limitation to this study is that we have not investigated whether patients' treatment beliefs change during rehabilitation. These changes in cognitions may be more strongly related to outcomes of rehabilitation than patients' pre-treatment beliefs. We suggest future studies to examine possible changes in patients' beliefs to further our understanding of the relation between patients' cognitions and treatment outcomes.

Notwithstanding these limitations, we feel that our study has some implications for clinical practice. The present study shows that patients' concerns about exercise are negatively related to walk test results, and response to treatment for patients with mild airflow impairment. Currently, COPD patients' concerns about treatment tend to be underrepresented in the communication between patients and healthcare providers (52). Therefore, we suggest that patients' treatment beliefs are discussed explicitly, preferably before the start of treatment. Uncovering patients' concerns about treatment may help physicians understand abnormal exercise test results that cannot be explained by physical parameters alone. Furthermore, correcting unrealistic fears and tailoring the program to the demands of the individual patient might not only improve treatment uptake and adherence but also can have a beneficial effect on treatment outcomes, in particular for patients with mild to moderate airflow obstruction.

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Appendix 1. Items covering perceptions about exercise.

Necessity

1. I have a clear picture of how pulmonary rehabilitation will improve the condition of my lungs.
2. I have a clear picture of what I want to achieve by attending pulmonary rehabilitation.
3. My physical condition will improve considerably if I attend the rehabilitation program for 12 weeks.
4. Some aspects of the rehabilitation program are unnecessary for me.*
5. I hope that attending pulmonary rehabilitation may help me resume my activities more quickly.

Concerns

1. Some aspects of the rehabilitation program may be harmful to me.
2. I may not be physically fit enough to participate in the rehabilitation program.
3. In the days in between the rehabilitation sessions I am probably very tired from exercising.

*This item was reverse scored.

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CHAPTER 7

General discussion

INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) is one of today's main public health problems. The disease is characterised by progressive airflow limitation and a range of extrapulmonary effects that contribute to the severity of the disease [1]. The illness process is associated with severe consequences for physical, psychological and social functioning of those affected. Epidemiologic data show that COPD is the only major disease for which the mortality rates have been increasing since the past 40 years [2].

Pharmacological therapy, self-management education, supervised physical exercise, smoking cessation interventions, nutritional counselling, and psychosocial support are the most effective treatment modalities for patients with COPD. These interventions are combined in pulmonary rehabilitation (PR), making it the most comprehensive and patient-centred treatment option for COPD. The ultimate goal of PR programmes is to restore patients to the highest possible level of independent functioning [3].

Pulmonary Rehabilitation has become a recommended type of care for patients with COPD. Many patients benefit from PR programmes in terms of improvement in quality of life and exercise tolerance, and a reduction in symptoms and healthcare utilisation. However, research has shown that a substantial proportion of the referred patients do not complete the programme or show suboptimal attendance, which has served as motive for the research described in this thesis. The overarching goal of the studies was to investigate the role of cognitive and emotional variables in patients' adherence to treatment during a PR programme.

Theoretical background of this thesis

The World Health Organisation has stated that patients' perceptions of their illness and treatment are crucial factors in patients' adherence to treatment [4], a view that has recently been recognized in the research and care for patients with COPD [5]. The Common Sense Model (CSM) by Leventhal and colleagues provides a conceptual framework for the comprehension of the relation between illness perceptions and adherence to treatment [6,7]. According to the CSM, individuals have acquired theories about health and illness that guide their interpretation of symptoms and illnesses. Based on the perceived seriousness and controllability of the condition, people will plan and execute a coping response to manage the illness and the accompanying emotional reactions. In this sense, adherence to treatment can be regarded as a specific way of coping with an illness [8].

According to the CSM, individuals will evaluate whether their coping efforts have brought them closer to a desired state (appraisal stage). The outcomes of this appraisal will feed back to the interpretation (the representation of illness) and action stages. This is a cyclical process that is expected to be continued until an acceptable outcome has been attained [9,10].

More recently, an extension to the original CSM was proposed by Horne [11]. It is proposed that not only representations of the illness but also the beliefs about treatment are predictive of adherence to treatment and, by influencing adherence, treatment outcomes. The framework assumes that individuals consider the perceived necessity of treatment and the concerns about the expected negative aspects of treatment [12]. The outcome of this evaluation influences the decision to adhere to a proposed treatment regimen.

Extending previous work in various patient populations by our research group at the Leiden University Medical Center (LUMC) Unit of Psychology [cf. Scharloo (2002), Helder (2002), van Korlaar (2006), Thong (2009), Godefroy (2010)][13-17], the purpose of this thesis was to use the CSM and the Necessity-Concerns framework in investigating perceptions of patients with COPD about their illness and their beliefs about rehabilitation, and to establish their relationship with treatment adherence and treatment outcomes. Specifically, the study has focused on four main research questions:

1) How do patients with COPD who are referred to a rehabilitation programme, perceive their illness and what do they expect from the rehabilitation programme?
2) How are perceptions of illness and treatment related to patients' drop-out and attendance in a pulmonary rehabilitation programme?
3) Do illness perceptions change after a rehabilitation programme, and is the individual's appraisal of the outcomes of rehabilitation related to post-treatment illness perceptions?
4) How are perceived treatment necessity and treatment concerns related to walking test results at baseline and at follow-up?

ILLNESS PERCEPTIONS OF PATIENTS WITH COPD

Patients' perceptions of COPD

Early research on illness perceptions has shown that people organise the content of their illness representations into five interrelated dimensions: the symptoms associated with the illness, its cause, the consequences for quality of life, the perceived degree of curability or controllability, and the expected timeline of the disease [6]. These five dimensions could be distinguished in our qualitative study (chapter 3). This study showed that most patients with COPD who had been referred to a pulmonary rehabilitation centre suffered from dyspnoea, chronic cough, fatigue and regular chest infections (symptoms), leading to disability, reductions in social participation and dependency on others (consequences). The incurable, progressive and often unpredictable nature of the disease gave rise to emotional reactions such as fear and frustration. All patients understood that they could not be cured (curability) and that their illness would be permanent and progressive (timeline). These negative perceptions about the illness sometimes caused patients to adopt modest expectations of the effectiveness of pulmonary rehabilitation (treatment control). Although most patients had been told by their physician that smoking was the main cause for COPD (cause), some were reluctant to accept COPD as a self-inflicted disease and suggested other causes beyond their own control may have been responsible, such as environmental pollution or occupational chemicals.

Illness perceptions and drop-out in rehabilitation

The CSM predicts that motivation to engage in health promoting behaviour is dependent on the individual's perceptions of the health threat. In line with these premises, results from interviews (chapter 3) showed that two specific perceptions appear to be related to patients' motivation to participate in pulmonary rehabilitation. Firstly, motivation was higher when the illness had more severe consequences for patients' quality of life. Secondly, patients were more motivated to participate in rehabilitation if they expected that the impact of their disease could be controlled by participating in the rehabilitation programme.

In our quantitative study (chapter 4) we could not confirm our hypothesis that illness perceptions distinguished those patients who completed the rehabilitation programme from those who declined treatment or dropped out prematurely. One reason for not finding a relationship between illness perceptions and drop-out could be the very low number of non-completers in our study. Only 12 out of 50 patients who did not complete the programme had made a deliberate decision not to start or finish the rehabilitation programme. As a result it was more difficult to detect statistically significant differences between those patients who decided to continue and those who decided to terminate their participation. Studies with larger numbers of drop-outs during rehabilitation (c.f. [18]) will have greater statistical power to demonstrate differences in illness perceptions between drop-outs and completers.

Another possible explanation is that illness perceptions may have a more powerful influence on patients' behaviour at an earlier stage, at a time when patients have to decide whether or not they are willing to go through the intake procedure at the rehabilitation centre. It is likely that patients who do not perceive their condition as serious enough to warrant a rehabilitation programme or who are not convinced that following such an intensive treatment will be worth the effort, will not even make an appointment for a first intake consultation. Assessing patients' illness perceptions before instead of after a first appointment in a rehabilitation centre probably will be more efficient to examine how illness representations guide patients' behaviour. For instance, Cooper and colleagues have assessed illness perceptions of patients who were hospitalised after a myocardial infarction or a coronary arterial bypass graft [19]. It was found that patients who had participated in a cardiac rehabilitation programme in six months after their hospital admission had different representations of their illness (having stronger perceptions of illness controllability and assuming greater personal responsibility for their cardiac condition) than those patients who had not attended a rehabilitation programme.

Illness perceptions and (non-)attendance in rehabilitation

With regard to the degree of attendance during the pulmonary rehabilitation programme we found that patients with higher attendance had stronger perceptions that their illness would be amenable to treatment than patients with lower attendance rates. This finding supports conclusions from a meta-analysis by French in which patients' perceptions about the controllability of the disease were found to be the most consistent predictor of attendance in a cardiac rehabilitation programme [20].

As for the other illness perception dimensions, differences between the 'high' and 'poor' attendance were not statistically significant, suggesting that other illness perceptions assessed with the Illness Perception Questionnaire-Revised (IPQ-R) do not have such as strong influence on patients' attendance compared with the perceptions about the effectiveness of treatment. The fact that differences in illness perceptions between the high and poor attendance groups did not reach significance may have had several reasons. Firstly, although it is a positive outcome in its own right that most patients had high attendance rates, this homogeneity made it less likely that a significant relationship between predictor (illness perceptions) and outcome variable (attendance) would be observed. Secondly, as illness perceptions exert their influence on volitional behaviour, causes of non attendance that were obviously beyond patients' control (e.g. hospital admissions or unforeseen doctor appointments) were excluded from the analysis. However, with regard to the reasons of non-attendance that were included in the analysis, it is not entirely clear to which degree these reasons reflect voluntary behaviour. The decision to spend a day with ones grandchildren or to skip a session because of an inconvenient training schedule is obviously under patients' own control. However, this is less clear when patients have physical complaints such as dyspnoea or a headache. Therefore, if it is true that non-attendance has in some cases been involuntary in nature, the observed relationship with patients' illness perceptions will have been attenuated.

Illness perceptions of patients with COPD in other studies

The IPQ-R was published in 2002 [21]. Since its publication, only two other studies have investigated illness perceptions among patients with COPD using this instrument. Scharloo and colleagues (2007) assessed illness perceptions among 171 consecutive patients attending an outpatient respiratory clinic [22]. Although age distribution and level of airflow obstruction (FEV_1 and FEV_1%pred) of patients in their study were comparable to those in our study (chapter 4), there were significant differences between the two studies in patients' perceptions of their condition. Compared with a typical outpatient population, patients in our study who were referred to a rehabilitation clinic experienced more negative consequences and had less confidence in their own abilities to control the illness. At the same time, patients in our study were more convinced that treatment would be effective in controlling their symptoms. Additionally, it appears that patients in our study had higher scores on the timeline cyclical subscale of the IPQ-R. Reasons for the higher perceived cyclical timeline are speculative but may relate to a greater frequency of exacerbations among the patients who were referred to a rehabilitation centre. This may lead patients to perceive COPD as an illness that is associated with periods of unpredictable aggravations. Given the fact that perceived consequences and treatment control are important factors in patients' adherence (chapters 3 and 4), the observed differences in perceptions may indicate that patients in our study are more prepared to follow an intensive rehabilitation programme than patients in an outpatient setting.

In a recent study, Howard and co-workers (2009) have used the IPQ-R to investigate how illness perceptions are related to panic attacks in patients with COPD [23]. In this study the authors demonstrated that patients who suffered from panic attacks attributed more symptoms to COPD, expected their illness to be more long-lasting and experienced more consequences from COPD than non-panickers. These findings could not be explained by differences in level of airflow obstruction. This study lends support to the Parallel Process Model [24] (chapter 1, p13) which postulates that cognitive and affective responses to an illness are closely related.

Outcome appraisal and change in illness perceptions

Self-regulation is a dynamic process. According to the CSM patients will monitor the outcomes of their efforts in coping with the illness, which may feed back on their representations of the illness. In line with this assumption, results from our study showed that illness perceptions were not static but appeared to change over the course of treatment (chapter 5). Treatment that was perceived as successful in bringing desired outcomes was associated with more positive illness perceptions post-treatment in terms of consequences of the illness, personal influence over the illness and variability in symptoms. Achieving one's treatment objectives during rehabilitation has therefore the potential to reverse the effects of declining health over time, which in many patients had led to the adoption of more pessimistic views about their illness.

In our interviews before the start of the rehabilitation programme, patients had stated that the absence of noticeable improvement in their condition (outcome appraisal) would be a reason for them to discontinue their participation in rehabilitation (chapter 3). However, data from chapter 5 showed that patients who were unsatisfied with the outcomes of treatment had also completed the programme. Explorative interviews with these patients revealed that moral obligation towards rehabilitation staff and the supportive and positive interactions with fellow patients served as justification to complete the programme. This finding suggests that in some cases there may be a gap between the goals set at the beginning of the rehabilitation and subsequent monitoring of goal progression and adjustment of treatment goals during treatment.

PATIENTS' BELIEFS ABOUT PULMONARY REHABILITATION

The development of treatment beliefs

Leventhal et al. [7] distinguish three sources of information for the elaboration of illness perceptions. We believe the same holds true for the development of treatment beliefs. Probably the most important source of information is one's previous experience with treatment. Results from our interviews showed that patients who had participated in PR before were more articulate about the potential benefits and drawbacks of rehabilitation (chapter 3). Newly referred patients were more careful in expressing expectations about the potential benefits of rehabilitation, fearing that they might prove unrealistic. Although illness perceptions of patients with prior experience in rehabilitation were comparable to perceptions of patients without prior participation in PR (chapter 5), additional analyses revealed that patients with prior experience in PR had stronger perceptions about the necessity and less concerns about PR than newly referred patients.

A second source of information is the generalized pool of treatment information current in a specific culture. It appears that there is a lack of awareness about PR programmes among patients with COPD, which may be due to the absence of public information about pulmonary rehabilitation[25]. In our interviews (chapter 3), newly referred patients associated PR with concepts such as fitness centres, gymnastics, and rehabilitation after accidents. Compared with returning patients, patients who had no prior experience in rehabilitation had a one-dimensional perception about rehabilitation, focused on the physical component of rehabilitation. By contrast, returning patients appreciated the multi-disciplinary character of rehabilitation.

A third source for the development of treatment beliefs is information obtained in direct contact with other people. From our interviews it appeared that, unless patients had previous experience in rehabilitation, patients relied to a large extent on second hand stories by fellow patients or recommendations by their referring healthcare provider for the formation of treatment perceptions (chapter 3). It is therefore important for healthcare professionals to provide patients with realistic information about the proposed treatment, but also to check how this information is interpreted by the patients.

Treatment beliefs and walk test results

Our results showed that patients' treatment beliefs were related to walk test results (six minute walk test), after correcting for variations in gender, age, height, weight and airflow obstruction (chapter 6). Concerns about the negative consequences of training proved to be negatively related to walk test performance at baseline. It was hypothesised that this was caused by patients' tendency to avoid dyspnoea and fatigue by refraining from strenuous exertion. Pulmonary rehabilitation has the aim of desensitising patients to the effects of dyspnoea and breaking the dyspnoea-inactivity-deconditioning cycle [26,27]. However, among patients with mild-to-moderate airflow obstruction, those who were more concerned at baseline about the negative side-effects of training had a lower chance to substantially increase their walk distance. This finding lends support to the assumption that psychological processes are important for understanding limitations in exercise capacity [28], but also for improving chances to achieve a successful treatment outcome.

Results from this study suggest that patients' concerns about pulmonary rehabilitation and exercise should be explored, discussed and, if necessary, corrected early during treatment. Unfortunately, in current medical practice the exploration and discussion of patients' concerns is uncommon [29].

LIMITATIONS

Certain limitations in relation to the results of the study presented in this thesis must be acknowledged. Firstly, with regard to drop-out and non-attendance the timing of the patient inclusion (during the first intake consultation at the rehabilitation centre) was convenient because it had the practical advantage of recruiting a large sample of patients in three rehabilitation centres. However, as stated above, patients who decline participation probably will not even make a first appointment in the rehabilitation clinic and could therefore not be identified in our study.

Another limitation in our study may be the self-selection of patients who agreed to take part in this study. We had introduced our study as 'a patient survey about beliefs about COPD and pulmonary rehabilitation' and did not explicitly state that we would keep track of drop-out and attendance records. Nonetheless, patients who accept their physician's invitation to take part in a scientific study are perhaps also inclined to comply with other requirements, such as the request to attend all scheduled appointments.

A third limitation is the fact that in studying drop-out and attendance, we had to rely on information from the patients' medical files or from the therapists work logs. These data however, may not always have been reliable. Reasons for non-attendance were often not available, either because no reason was provided by patients or the reason was not recorded in the therapists' log files. As a result, 30% of non-attendance had an unknown cause. Additionally, with regard to drop-out we discovered that reasons patients gave us for dropping out sometimes differed from those that had been recorded in patients' medical files. Apparently, some patients feel uncomfortable admitting to their therapists that they don't want to continue their rehabilitation programme or prefer to skip a single day.

Finally, the assessment of post-treatment illness perceptions was not part of the original study protocol. However, as there is a lack of studies investigating a possible change in illness perceptions from pre- to post-treatment, this was considered a relevant theoretical research question. Therefore, we decided to add a post-treatment assessment of illness perceptions during the course of our study. We have investigated the change in illness perceptions in 87 of the 217 patients who took part in our study.

SUGGESTIONS FOR FUTURE RESEARCH & PRACTICE

Research implications

Based on the results from our studies we can formulate some recommendations for future research. First of all, to increase our understanding of how patients' perceptions of COPD influence their decisions to follow a rehabilitation programme, we suggest future studies to assess patients' illness representations at an earlier stage. Illness perceptions could be assessed at an outpatient clinic or when patients are admitted for an exacerbation to examine their influence on patients' decision making. Based on a comparison with the Scharloo study [22], we expect that patients who will participate in rehabilitation will not differ from those who decline treatment with regard to pulmonary functioning, but will hold different views about their illness.

Secondly, we have demonstrated that a positive appraisal of the outcomes of participating in rehabilitation is related to more positive perceptions of COPD. In line with the self-set treatment goals in chapter 3, our results showed that positive appraisal was related to an increase in distance walked and a decrease in symptoms of dyspnoea and fatigue (chapter 5). This has been one of the first studies within the Common Sense Model that has focused on the appraisal stage and its proposed feedback on patients' illness perceptions. Further research is needed to establish the relationship between patients' self-selected treatment objectives and the effect of the perceived achievement of these objectives on post-treatment illness perceptions.

Furthermore, from our interviews it became clear that some patients wish to avoid performing worse than others, which raises the question of how patients define their treatment goals. A relevant question for future studies is therefore whether patients are comparing their current performance with their own previous performance (mastery goals) or with the performance of others (performance goals) [30,31], and how this goal orientation is related to motivation, and the perception of goal accomplishment.

Leventhal and colleagues [6 p26] suggest that perceptions about illness are more differentiated and robust than perceptions about the coping efforts. It can therefore be expected that the appraisal phase has more influence on beliefs about treatment than on illness perceptions. In order to investigate this assumption it is necessary that illness perceptions and treatment beliefs are assessed before and after treatment. It can then be determined whether the appraisal of the achievement of treatment goals shows a stronger relationship with post-treatment beliefs about rehabilitation than with the perceptions of COPD.

Results from chapter 6 suggest that concerns about exercise are related to walk test results. To further clarify the influence of treatment concerns on physical outcomes, these perceptions should be related to outcomes from other physical tests such as the submaximal cycle ergometer test or shuttle walk test. Also, if it is true that patients avoid exercising to the maximum of their capabilities, this should be observed during training. More research is needed to investigate the possible relationship between patients' treatment perceptions and indices of patients' effort during physical training (e.g. Borg fatigue scores, amount of calories burnt, oxygen uptake, percentage of maximum heart rate).

Finally, this thesis has used the Common Sense Model and the Necessity-Concerns framework as a theoretical background for the investigation of patients' behaviour during pulmonary rehabilitation. The CSM and the Necessity-Concerns framework consider perceptions of illness and treatment beliefs as the principle factors in explaining patients' motivation to engage in health protective behaviour. Both models emphasise the importance of the degree to which one perceives the illness as controllable by treatment or self-care (outcomes expectancies) in determining patients' behaviour. However, there is relatively little emphasis on patients' confidence in the ability to execute the behaviours which are deemed necessary to attain a desired outcome (self-efficacy expectancies), as self-efficacy is considered "less important for a substantial proportion of illness behaviours" [9]. However, our interviews have demonstrated that with regard to rehabilitation, positive expectations about the outcomes of treatment are not sufficient for the decision to follow treatment. Including the concept of self-efficacy in future studies may improve the prediction of uptake and adherence in pulmonary rehabilitation. In line with our observations from the interviews (chapter 3) and prominent theories on health behaviour (e.g. Theory of Planned Behaviour [32], Social Cognitive Theory [33], Health Action Process Approach [34] or Protection Motivation Theory [35]), we suggest that self-efficacy is a relevant concept for many health-related behaviours for patients with COPD. Recent studies have shown that patients' illness perceptions are related to the concept of self-efficacy and that both patients' interpretation of the illness as well as their self-efficacy expectations are related to attendance at a rehabilitation programme [36,37].

Practice implications

Self-regulation models provide a useful framework for clinicians who seek to understand patients' adherence to treatment regimens and, as a consequence, treatment outcomes. According to Horne [12] and Lau-Walker [38], a few elements are important in patients' motivation to follow treatment. First of all, patients must perceive their condition as a serious, yet controllable illness (illness perceptions) before they start searching for a solution. Secondly, patients must decide between the available methods of coping with the illness. The decision to follow an intensive rehabilitation programme is more likely when patients believe the benefits will outweigh the concerns (treatment beliefs). Thirdly, patients need to feel confident that they are able to meet the challenge of complying with the treatment regimen (self-efficacy). Practice implications pertain to these three elements.

First of all, during our interviews (chapter 3) we observed that some of the referred patients were only mildly impaired and did not know why they had been referred to a rehabilitation centre. This suggests that these patients might have been referred too soon to be sufficiently motivated to engage in treatment. On the other end of the spectrum we spoke with severely disabled patients who were unsure whether anything could be done for them. COPD was conceptualised by these patients as an incurable and progressive disease, which provoked fatalism and passive coping responses. As illness perceptions are important for uptake and attendance, we suggest rehabilitation centres to assess and discuss patients' illness beliefs prior to the start of the rehabilitation. The Illness Perception Questionnaire-Revised (IPQ-R) or the recently developed 9-item Brief-IPQ (both available from: http://www.uib.no/ipq/) could easily be used as routine screening instrument together with other frequently used tools to assess psychosocial variables, such as the Chronic Respiratory Questionnaire (CRQ) and St. George's Respiratory Questionnaire (SGRQ) for quality of life, and the Hospital Anxiety and Depression Scale (HADS) or Beck Depression/Anxiety Inventory (BDI/BAI) for mood disturbances. Patients who report pessimistic perceptions about their condition and treatment might be candidates for additional counselling. Techniques to discuss illness perceptions with patients can be learned quickly [39] and previous studies have shown that psycho-educational interventions are successful in changing maladaptive illness perceptions [40-44], especially when they are delivered at a time in which patients are more inclined to change, for instance after an exacerbation [25,45].

With regard to treatment beliefs, in line with others [46,47] it is our observation that many patients are unaware about the existence of PR and have incorrect perceptions about what rehabilitation entails. Patients should be informed more extensively about pulmonary rehabilitation, as an integrated element in the treatment for COPD. Through mass media (television, health magazines, internet) patient organisations and rehabilitation centres play an important role in informing patients with COPD about the content and goals of pulmonary rehabilitation. It is imperative that the information about the programme is realistic and provides details about potential benefits and drawbacks. Stories of patients who have participated in rehabilitation before may serve as a potent source of information for the formation of treatment beliefs. Chest physicians are the primary source of information for their patients and logically patients rely on the advice given by their referring physician [46,48,49]. Therefore it is necessary that not only patients but also chest physicians are properly educated about the place of PR in the continuum of care for patients with COPD and that they understand which patients are candidates for referral. Currently, training for chest physicians in the Netherlands only briefly touches on the topic of pulmonary rehabilitation.

Finally, participation in PR requires a lot of effort from patients who are often severely disabled. Patients need to feel confident they can overcome the many physical, organisational and social challenges they are facing in completing the 12-week programme. These perceived barriers can force patients to decide to decline treatment, even if they expect the programme to be beneficial. In supporting patients' sense of self-efficacy, the interaction between patient and healthcare provider plays an essential role. Firstly, healthcare providers need to discuss explicitly the obstacles patients expect in completing the programme and accommodate the intervention where possible to meet the unique needs and limitations of the patient [50]. Inpatient programmes can solve some of the organisational problems for patients (e.g. transportation, daily household chores), although they may introduce other challenges (e.g. home sickness, limited privacy, having to share a room with another patient for 12 weeks). Collaboration between patients and rehabilitation providers is necessary to select the type of rehabilitation that is acceptable for both parties. Furthermore, rehabilitation providers need to be fair about what patients can expect. Patients must be explained the purpose of intensive training, should be taught to distinguish bothersome symptoms from threatening signs and need to be prepared that they cannot expect benefits immediately, to prevent early drop-out. At the same time patients need to be encouraged and must be convinced that training is appropriate for them and that the intensity of the training will be adjusted to their individual capabilities. Patients' self-efficacy can also be strengthened by observing other, more experienced, patients in the rehabilitation programme. Fellow patients provide powerful examples of how to deal with the challenges associated with participation in a rehabilitation programme. A buddy system, matching new patients with more experienced patients, might prove as a useful strategy in this regard.

Finally, self-efficacy is both a precursor and a consequence of successful performance. The process of goal setting, goal monitoring and goal adjustment is important for the development of patients' self-efficacy. Besides being specific and measurable, challenging and personally relevant, it is of utmost importance that goals are attainable. The level of difficulty of treatment objectives, set at the beginning of treatment should be tailored to patients' initial self-efficacy. Self-efficacy and perceptions about the illness can be expected to become more optimistic when individuals manage to achieve their treatment objectives. It is therefore important that the first goals patient will work on have a high chance to be achieved within a limited time.

In conclusion, this thesis has shed some new light on the role of patients' perceptions about their illness and treatment in explaining treatment adherence and outcomes in a comprehensive pulmonary rehabilitation programme. Although these results call for further investigation, we are convinced a self-regulation perspective provides a useful conceptual background for understanding and intervening in patients' behaviour during treatment.

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Summary

Chronic Obstructive Pulmonary Disease (COPD) is one of today's main public health problems. The illness process is associated with severe consequences for physical, psychological and social functioning of those affected and no cure is currently available. Pulmonary rehabilitation (PR) is one of the main non-pharmacological treatment modalities for patients with COPD. The ultimate goal of PR programmes is to restore patients to the highest possible level of independent functioning. In spite of the evidence supporting the benefits for patients, pulmonary rehabilitation programmes have considerable drop-out rates, varying between 20-40%. These rates cannot be explained by illness factors or practical barriers alone.

According to Leventhal et al.'s Common Sense Model of Self-Regulation (CSM) and the extension to the CSM, the Necessity-Concerns framework, self-management behaviour (including adherence to treatment) and subsequent health outcomes are guided by the individual's representations of illness and treatment. The purpose of this thesis was to use the CSM as a theoretical framework to examine how beliefs about illness and rehabilitation are related to treatment adherence and treatment outcomes. This study focused on four research questions:

1) How do patients with COPD who are referred to a rehabilitation programme, perceive their illness and what do they expect from the rehabilitation programme?
2) How are perceptions of illness and treatment related to patients' drop-out and attendance in a pulmonary rehabilitation programme?
3) Do illness perceptions change after a rehabilitation programme, and is the individual's appraisal of the outcomes of rehabilitation related to his or her post-treatment illness perceptions?
4) How are perceived treatment necessity and treatment concerns related to walking test results at baseline and at follow-up?

Chapter one outlines the theoretical foundations of self-regulation of health and illness, which serve as guiding principles for this thesis. The chapter describes Leventhal et al.'s Common Sense Model and Horne's extension to the CSM: the Necessity-Concerns framework. The concepts of illness perceptions and treatment perceptions are introduced and previous research on the relationship between patients' adherence and perceptions of illness and treatment is reviewed.

Chapter two presents an introduction to COPD and pulmonary rehabilitation. In the first part of the chapter, epidemiological data are presented, and the physical, emotional, social and cognitive impact of COPD is described. The second part of the chapter provides a general overview of the organisation and components of pulmonary rehabilitation and the selection of patients. In separate paragraphs the effects of pulmonary rehabilitation on physical, emotional, social and cognitive functioning are reviewed.

Illness perceptions and beliefs about pulmonary rehabilitation of patients with COPD who were referred to a rehabilitation clinic are presented in **chapter three.** Twelve patients were interviewed before the start of the rehabilitation programme. Results showed that all patients knew their illness would be life-long and that there was currently no cure available for COPD. Most patients experienced serious consequences with regard to physical symptoms and psychosocial well-being. Perceived necessity for treatment appeared to be reduced when patients experienced only mild impairment.

Expectations about the benefits of rehabilitation were dependent on previous experience with PR or strength of referral by their chest physician. Patients understood their participation was not without costs, although for most patients the expected benefits outweighed the costs. When patients perceived the need for treatment to be low, they were also less concerned about the drawbacks of the programme, as they expected they could terminate their participation at any time.

Patients had several ideas about factors that would hinder their participation and might cause them to drop out, such as the intensity of the programme overtaxing their physical resources, practical barriers (e.g. respiratory infections, transportation problems, other duties), the absence of noticeable improvement throughout the programme and social factors such as homesickness or conflicts with other patients or staff.

Confirming assumptions of the Common Sense Model, the perceived severity of the illness and the expected positive and negative outcomes of treatment contributed to patients' motivation to participate in PR. Additionally, the data suggest that patients' motivation to participate in the rehabilitation programme is related to patients' confidence in their ability to comply with treatment.

In **chapter four** the participation and non-completion rates of 217 patients with COPD who had been referred to a pulmonary rehabilitation programme were examined. The aim of this prospective study was to document reasons for non-completion and non-attendance during a 12-week PR programme. A second aim of this study was to examine the possible relation of drop-out and non-attendance with sociodemographic and clinical variables and illness perceptions. Prior to the start of the rehabilitation programme, patients filled out the Illness

Perception Questionnaire-Revised (IPQ-R). Clinical data were extracted from patients' medical files.

Fifty patients (23%) did not complete the programme, frequently because of COPD-related factors, such as exacerbations and hospitalisations. Other causes were exclusion of patients by the rehabilitation team (because of comorbidity or limited expected benefits of PR) and patients declining treatment (because of other activities they preferred not to postpone, dissatisfaction with the treatment organisation, financial difficulties, homesickness and relocation). No differences were found in sociodemographic and clinical variables or illness perceptions. This is probably due to the wide variety in uncontrollable and unforeseen reasons for non-completion.

Patients attended 92% of all scheduled appointments (range 61-100%). In 31% of missed appointments no reason was provided by patients for their non-attendance or the reason was not documented in patients' medical files. When reasons were documented, COPD-related complaints, non-COPD symptoms (e.g. migraine), leisure activities (e.g. attending a wedding) and unforeseen doctor appointments were frequently cited as reasons for absence. A hierarchical logistic regression analysis showed that a higher Fat Free Mass Index and stronger perceptions about the effectiveness of treatment (IPQ-R 'treatment control') were associated with more frequent attendance during the programme.

In sum, adherence to rehabilitation appears to be satisfactory. However, we conclude that paying attention to patients' nutritional status and creating positive expectations of treatment during referral and intake are important if one aims to optimize patients' attendance during rehabilitation.

In **chapter five** the dynamics of patients' illness representations were investigated. Within the CSM, two processes have been suggested to influence the evolution of illness perceptions over time. Firstly, the CSM assumes that when confronted with an illness, individuals initially tend to perceive the condition in acute terms. However, if the disease is chronic, this 'acute' illness model in time will be replaced by a 'chronic' model (e.g. stronger perceptions about the permanent nature of the illness, more experienced consequences, and diminished perceived controllability). Secondly, as the CSM is a cyclical model, illness perceptions are thought to be reshaped by the outcomes of coping with the illness. As adherence to treatment can be regarded as a way of coping with an illness, the perceived success of this treatment is expected to be related to post-treatment illness perceptions.

In 87 patients with COPD the IPQ-R was administered before and after completion of pulmonary rehabilitation. Confirming the first hypothesis, baseline data showed that longer time since diagnosis was associated with more negative experienced consequences of COPD and stronger chronic timeline perceptions. By contrast, perceptions of personal and treatment control were inversely related to time since diagnosis. The association between time since diagnosis and illness perceptions could be demonstrated after correcting for differences in patients’ level of airway obstruction, exercise tolerance and Body Mass Index. These results lend support to the acute-to-chronic illness model hypothesis.

There was also support for the second hypothesis. 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 variability in symptoms and had increased personal control perceptions. We conclude that in chronically ill patients representations of their illness change over time and that a change in illness perceptions partly depends on the appraisal of one’s coping efforts. This has practical implications for the choice of treatment objectives. Objectives that are both relevant and have a good chance of being achieved may have the beneficial side effect of changing patients’ representations of COPD in a positive direction. By contrast, unrealistic goals may lead to disappointment and a more pessimistic view of the condition after treatment.

Chapter six uses the Necessity-Concerns framework as a theoretical background to investigate the association of patients’ treatment perceptions with their walk test results. The expectation was that, after correction for differences in clinical variables, perceived necessity of rehabilitation would be positively related to patients’ walk distance whereas concerns about rehabilitation would show a negative relationship. In this study 166 patients had filled out a questionnaire about the perceived necessity and concerns regarding rehabilitation before the start of treatment. Six-Minute Walk Test (6MWT) results served as the outcome variable. Results showed that patients’ concerns about treatment were related to poorer baseline walk test results after correcting for sex, age, weight, height and airway obstruction. Treatment necessity was unrelated to walk test results.

Next, we investigated whether perceptions about exercise were related to an improvement in distance walked after the rehabilitation programme. This analysis showed that the influence of perceptions varied depending on patients’ lung function. Among patients with mild-to-moderate disease (GOLD I/II), having serious concerns about treatment reduced chances of achieving a clinically significant improvement in walk distance (more than 10% increase). Of the patients with only minor concerns 73% had achieved this 10% increase in walk distance, whereas of the patients with many concerns only 44% percent of the patients had achieved this meaningful effect of treatment.

In patients with severe or very severe disease the opposite result was found. Contrary to our hypothesis, patients with no or minor concerns about exercising had a smaller chance to improve their walk distance, compared with those who had many concerns. Possibly the absence of concerns about exercise in patients with severe airway obstruction reflected an inefficient coping style. Treatment goals for these patients may therefore have been focused on promoting adjustment to the illness and teaching energy conservation skills, instead of strenuous exercise to improve physical fitness.

This study demonstrates that psychological factors such as patients' perceptions about treatment are important when interpreting exercise test results. Patients' concerns need to be discussed during intake phase. Currently, patients' concerns about treatment tend to be underrepresented in the communication between the patient and healthcare provider. However, if unrealistic negative perceptions about treatment can be elicited and dealt with, this should not only improve uptake and adherence to rehabilitation but might also have a beneficial effect on treatment outcome.

In **chapter seven** the main results of this thesis are summarized and discussed. We conclude that the Common Sense Model and the Necessity-Concerns framework are useful conceptual models for understanding patients' adherence and exercise test results in pulmonary rehabilitation. We propose that perceptions of illness and treatment be included along with the physical variables as part of the routine assessment during the intake phase. Given the importance of patients' perceptions in self-management behaviour, it is our opinion that patients' perceptions have practical value for patient selection for PR, and changing perceptions should be considered as one of the possible treatment objectives for the individual patient.

Samenvatting

Chronisch obstructief longlijden (Chronic Obstructive Pulmonary Disease; COPD) is momenteel een van de belangrijkste gezondheidsproblemen in de wereld. De ziekte gaat gepaard met ernstige gevolgen voor het fysiek, emotioneel en sociaal functioneren van de patiënten en er is tot op heden geen genezing mogelijk. Longrevalidatie is één van de belangrijkste niet-farmacologische behandelingsmethoden voor patiënten met COPD. Het uiteindelijke doel van longrevalidatie is de patiënt zoveel mogelijk in staat te stellen zelfstandig met zijn of haar aandoening te functioneren. Ondanks dat de opbrengsten voor patiënten van dergelijke programma's herhaaldelijk zijn aangetoond, laten longrevalidatieprogramma's aanzienlijke uitvalpercentages zien, varierend tussen de 20-40%. Deze percentages kunnen niet door ziektefactoren of praktische barrières alleen worden verklaard.

Volgens het Common Sense Model (CSM) van Leventhal en collega's, en de uitbreiding van het CSM, het Necessity-Concerns framework, wordt self-management gedrag (waar therapietrouw onder kan worden geschaard) gestuurd door de representaties van de ziekte en behandeling van de individuele patiënt. Het doel van dit proefschrift was om het CSM als theoretisch kader te gebruiken waarbinnen onderzocht werd hoe ziektepercepties en opvattingen over longrevalidatie bij patiënten met COPD verband houden met therapietrouw en uitkomsten van het revalidatieprogramma. Concreet heeft dit onderzoek zich gericht op vier onderzoeksvragen:

1) Welke opvattingen hebben patiënten met COPD die verwezen zijn naar een longrevalidatieprogramma over hun ziekte en wat verwachten zij van de revalidatiebehandeling?
2) Hoe zijn ziekte- en behandelpercepties gerelateerd aan uitval uit het programma en de mate waarin patiënten aanwezig zijn tijdens het longrevalidatieprogramma?
3) Veranderen ziektepercepties na een longrevalidatieprogramma, en is de manier waarop iemand de opbrengsten van het programma beoordeelt gerelateerd aan zijn of haar ziektepercepties na afloop van de behandeling?
4) Zijn de waargenomen noodzaak en de zorgen met betrekking tot het revalideren gerelateerd aan resultaten op de looptest voorafgaand en na afloop van het programma?

Hoofdstuk een schetst de theoretische achtergrond van het begrip zelfregulatie van gezondheid en ziekte, die dient als leidraad voor dit proefschrift. Het hoofdstuk beschrijft Leventhal et al.'s Common Sense Model of Self-Regulation (CSM) en Horne's uitbreiding van het CSM: het Necessity-Concerns framework. De begrippen van ziekte- en behandelpercepties worden geïntroduceerd en eerder onderzoek naar de relatie tussen therapietrouw en ziekte- en behandelpercepties wordt samengevat.

Hoofdstuk twee bevat een introductie tot COPD en longrevalidatie. In het eerste deel van het hoofdstuk worden epidemiologische gegevens gepresenteerd. Daarna worden de fysieke, emotionele, sociale en cognitieve gevolgen van COPD beschreven. Het tweede deel van het hoofdstuk geeft een algemeen overzicht van de organisatie en onderdelen van een longrevalidatieprogramma en de selectie van patiënten. In afzonderlijke paragrafen worden de effecten van longrevalidatie op fysiek, emotioneel, sociaal en cognitief functioneren samengevat.

Ziektepercepties en ideeën over longrevalidatie van patiënten met COPD die naar een revalidatiecentrum waren verwezen worden gepresenteerd in **hoofdstuk drie**. Twaalf patiënten werden geïnterviewd voorafgaand aan de start van het revalidatieprogramma. Uit de interviews kwam naar voren dat alle patiënten wisten dat hun ziekte de rest van hun leven zou duren en dat er momenteel geen behandeling bestond die hen zou genezen. De meeste patiënten ervoeren ernstige gevolgen van hun ziekte met betrekking tot lichamelijke symptomen en psychosociaal welbevinden. De ervaren noodzaak voor de revalidatie leek lager te zijn wanneer patiënten slechts milde beperkingen ervoeren.

Verwachtingen over de voordelen van het revalidatieprogramma waren afhankelijk van eerdere persoonlijke ervaringen met revalideren of de sterke van de overtuiging waarmee het programma door hun arts werd aanbevolen. Patiënten meenden dat hun deelname ook nadelen met zich meebracht, hoewel voor de meeste patiënten de verwachte voordelen zwaarder wogen dan de nadelen. Wanneer patiënten de noodzaak van het revalideren als laag inschatten, maakten zij zich minder zorgen over de nadelen van het revalideren, aangezien ze meenden hun deelname aan het programma op elk moment te kunnen staken.

Patiënten hadden verschillende ideeën over factoren die een belemmering zouden kunnen vormen voor hun deelname of die ertoe zouden kunnen leiden dat ze het programma niet zouden kunnen voltooien, zoals wanneer de zwaarte van het trainingsprogramma hun fysieke vermogens zou overstijgen, praktische barrières (bijv. luchtweginfecties, vervoersproblemen, andere verplichtingen), het uitblijven van een merkbare verbetering tijdens het programma en sociale factoren zoals heimwee of conflicten met andere patiënten of medewerkers in het revalidatiecentrum.

De resultaten uit dit hoofdstuk laten zien dat, overeenkomstig de aannames van het Common Sense Model, de waargenomen ernst van de ziekte en de verwachte positieve en negatieve uitkomsten van de behandeling bijdragen aan de motivatie van patiënten om deel te nemen aan longrevalidatie. Daarnaast lijkt de motivatie om aan een longrevalidatie deel te nemen te zijn gerelateerd aan het vertrouwen van patiënten dat ze aan de eisen van het programma kunnen voldoen.

In **hoofdstuk vier** is de deelname en uitval onderzocht van 217 patiënten met COPD die naar een longrevalidatieprogramma waren verwezen. Het doel van deze prospectieve studie was de redenen te inventariseren voor uitval en afwezigheid tijdens een 12 weken durend longrevalidatieprogramma. Een tweede doel was de mogelijke relatie te onderzoeken tussen uitval en afwezigheid enerzijds en sociaal-demografische en klinische variabelen en ziektepercepties anderzijds. Voorafgaand aan het begin van het revalidatieprogramma, vulden patiënten een vragenlijst in met daarin sociaal demografische variabelen en de Illness Perception Questionnaire-Revised (IPQ-R). Klinische gegevens werden uit de status verzameld.

Vijftig patiënten (23%) voltooiden het programma niet, vaak als gevolg van COPD-gerelateerde factoren, zoals exacerbaties en ziekenhuisopnames. Andere oorzaken waren de exclusie van de patiënten door het revalidatiecentrum (als gevolg van comorbiditeit of beperkte verwachte opbrengsten van revalidatie) of patiënten die zelf besloten niet te starten of door te gaan (wegens andere activiteiten die men niet wilde uitstellen, ontevredenheid met de behandeling, financiële moeilijkheden, heimwee en verhuizing). Er werden geen verschillen aangetoond in sociaal-demografische en klinische variabelen of in ziektepercepties tussen patiënten die het programma afmaakten en patiënten die dat niet deden. Dit is waarschijnlijk toe te schrijven aan de grote verscheidenheid in oncontroleerbare en onvoorziene redenen voor uitval.

Patiënten waren aanwezig tijdens 92% van alle geplande afspraken (range 61-100%). In 31% van de gemiste afspraken was door patiënten geen reden gegeven voor hun afwezigheid of was deze reden niet gedocumenteerd in de status van de patiënt. Als de redenen wel waren gerapporteerd bleken COPD-gerelateerde klachten het meest genoemd als reden voor afwezigheid. Overige vaak gerapporteerde redenen waren COPD-ongerelateerde klachten (bijvoorbeeld migraine), activiteiten buiten het revalidatieprogramma om (bijvoorbeeld een bruiloft bijwonen) en onvoorziene afspraken bij de dokter. Een hiërarchische logistische regressie analyse toonde aan dat een hogere vetvrije massa index en groter vertrouwen in de effectiviteit van de behandeling (IPQ-R ‘treatment control’ subschaal) gerelateerd waren aan een hogere mate van aanwezigheid tijdens het programma.

Samengevat, de therapietrouw tijdens longrevalidatie lijkt bemoedigend. Echter, we concluderen dat het belangrijk is om aandacht te besteden aan de voedingsstatus van patiënten en een positieve verwachting van de revalidatie te creëren rondom het moment van verwijzing en intake wanneer men de aanwezigheid van patiënten tijdens de revalidatie wil optimaliseren.

In **hoofdstuk vijf** is de dynamiek van ziektepercepties onderzocht. Binnen het Common Sense Model worden twee mogelijke processen gesuggereerd die een verandering in ziektepercepties zouden beïnvloeden. Ten eerste wordt er binnen het CSM van uitgegaan dat, wanneer men geconfronteerd wordt met een ziekte, men aanvankelijk geneigd is de aandoening als acuut en voorbijgaand te zien. Echter, indien de ziekte chronisch is, zal dit 'acute' ziektemodel op termijn vervangen worden door een 'chronisch' ziektemodel, (bijv. een langere verwachte duur van de ziekte, meer ervaren consequenties van de ziekte en een lager gevoel van controleerbaarheid). Ten tweede wordt verondersteld dat ziektepercepties worden bijgesteld onder invloed van de uitkomsten van de inspanningen om met de ziekte om te gaan. Aangezien het volgen van een behandeling kan worden beschouwd als een specifieke vorm van omgaan met ziekte, kan verwacht worden dat de mate waarin een persoon deze behandeling als succesvol ziet van invloed is op de ziektepercepties na afloop van de behandeling.

Bij 87 patiënten met COPD is de IPQ-R zowel vóór als na de longrevalidatie afgenomen. In overeenstemming met de eerste hypothese, bleek bij de meting voorafgaand aan de revalidatie dat een langere tijd sinds diagnose geassocieerd was met meer negatieve gevolgen van COPD en een langer verwachte tijdsduur van de ziekte. Omgekeerd bleken het gevoel van persoonlijke controle en het verwachte effect van de behandeling negatief gerelateerd aan de tijd sinds diagnose. De associatie tussen de tijd sinds de diagnose en de ziektepercepties bleef zichtbaar na correctie voor verschillen in de mate van luchtwegobstructie, inspanningstolerantie en Body Mass Index. Deze resultaten bevestigen de hypothese dat ziektemodellen over tijd verschuiven van acuut naar chronisch.

Het onderzoek vond ook bevestiging voor de tweede hypothese. Na voltooiing van het revalidatieprogramma bleek dat patiënten, die meenden dat hun deelname aan het programma had geleid tot het bereiken van gewenste resultaten, minder bezorgd waren over de negatieve gevolgen van COPD, meer overtuigd waren van de variabiliteit in hun klachten, en een sterker gevoel hadden van persoonlijke controle over de ziekte. Wij concluderen dat ziektepercepties veranderen over tijd en dat deze verandering in ziektepercepties deels afhangt van hoe men de uitkomsten van zijn of haar inspanningen om met de ziekte om te gaan (coping) beoordeelt. Dit gegeven heeft praktische implicaties voor de keuze van behandeldoelen voor de revalidatie. Uitdagende maar haalbare doelen kunnen het gunstige neveneffect hebben dat ze leiden tot een verschuiving van ziektepercepties in positieve richting. Onrealistische doelen daarentegen zullen waarschijnlijk tot teleurstelling leiden en daarmee tot een meer pessimistisch beeld van de aandoening na afloop van de behandeling.

Hoofdstuk zes gaat uit van Horne's Necessity-Concerns framework als theoretisch kader waarbinnen de relatie wordt onderzocht tussen behandelpercepties en de resultaten van de looptest. De verwachting was dat, na correctie voor verschillen in klinische variabelen, de waargenomen noodzaak van revalidatie positief gerelateerd zou zijn aan de loopafstand, terwijl de zorgen over het revalideren een negatief verband zouden laten zien. In dit onderzoek hebben 166 patiënten vóór het begin van het programma een vragenlijst ingevuld over de waargenomen noodzaak en de nadelen (necessity & concerns) van de revalidatie. De 6-minuten looptest (6MWT) diende als uitkomstvariabele. De resultaten lieten zien dat de verwachte nadelen van de behandeling gerelateerd waren aan een slechtere looptest (voorafgaand aan de behandeling) na correctie voor verschillen in biomedische parameters (geslacht, leeftijd, gewicht, lengte en luchtwegobstructie). De waargenomen noodzaak van de behandeling was daarentegen niet gerelateerd aan de resultaten op de looptest.

Vervolgens is onderzocht of percepties van de behandeling van invloed waren op de verbetering in loopafstand na de behandeling. Uit deze analyse bleek dat percepties niet voor alle patiënten dezelfde invloed hadden op de verbetering in loopafstand, maar dat de invloed van de zorgen over het programma beïnvloed werd door de longfunctie van patiënten. Bij patiënten met een relatief goede longfunctie (GOLD I/II) bleek dat wanneer dezen zich meer zorgen maakten over het revalideren, zij minder kans hadden om hun loopafstand significant te verbeteren (meer dan 10% ten opzichte van baseline). Van de patiënten die zich weinig zorgen maakten haalde 73% die grens van 10% toename in loopafstand, terwijl dit voor patiënten die zich veel zorgen hadden gemaakt slechts 44% was.

Het omgekeerde verband werd gevonden voor patiënten met een slechtere longfunctie. In tegenstelling tot onze verwachting bleek binnen deze groep dat patiënten die zich geen of weinig zorgen maakten over de revalidatie een kleinere kans hadden om hun loopafstand te verbeteren dan zij die zich meer zorgen maakten. Mogelijk reflecteert de afwezigheid van bedenkingen over inspanning bij patiënten met ernstige luchtwegobstructie een inefficiënte manier van omgaan met de ziekte. Vermoedelijk zijn tijdens de revalidatie de behandeldoelen gericht geweest op het zich aanpassen aan de ziekte en het leren verdelen van beschikbare energie, in plaats van op intensieve training om de fysieke conditie te verbeteren.

Deze studie toont aan dat psychologische factoren, zoals opvattingen van patiënten over de behandeling belangrijk zijn bij de interpretatie van inspanningstesten. De ideeën over de mogelijk nadelige effecten van inspanning moeten derhalve worden besproken tijdens het intakegesprek. In de huidige praktijk blijken zorgen van patiënten over de behandeling te weinig aan bod te komen tijdens gesprekken tussen patiënt en zorgverlener. Echter, wanneer onrealistische negatieve gedachten over de behandeling kunnen worden verhelderd en gecorrigeerd, zou dit niet alleen kunnen leiden tot een betere therapietrouw, maar ook tot gunstiger resultaten van de behandeling.

In **hoofdstuk zeven** zijn de belangrijkste resultaten van dit proefschrift samengevat. We concluderen dat het Common Sense Model en het Necessity-Concerns framework zinvolle conceptuele modellen zijn voor het begrijpen van therapietrouw en resultaten van inspanningstesten in longrevalidatieprogramma's. Onze aanbeveling is dat ziekte- en behandelpercepties worden geïncludeerd tezamen met de fysieke variabelen als onderdeel van de standaard evaluatie tijdens de intakefase van een longrevalidatieprogramma. Gegeven het belang van de overtuigingen van patiënten voor het self-managementgedrag, zijn wij van mening dat percepties van patiënten een praktische waarde hebben in de selectie van patiënten, en het veranderen van percepties zou overwogen moeten worden als één van de mogelijke behandeldoelen voor de individuele patiënt.

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Curriculum Vitae

Publications

Curriculum Vitae

Maarten Fischer was born on January 20th, 1976 in Nijmegen. After completing secondary education (Stedelijk Gymnasium Nijmegen) in 1994, he studied Psychology at Groningen University. He obtained his Masters degree in Social Psychology and completed a Minor in Clinical Psychology (2000). From 2000 to 2004 he worked as a research assistant at the Helen Dowling Institute for Psycho-oncology in Utrecht, on a project about Quality of Life of men with prostate cancer. From 2004 to 2008 he was a PhD-student at the Unit of Medical Psychology of Leiden University Medical Center (LUMC) on a project about illness representations and treatment perceptions of patients with COPD, of which the results are described in this thesis. In December 2008 he began working as a research psychologist at the Department of Clinical Oncology (LUMC), on a project supported by Pink Ribbon which aims to optimise psychosocial care for women with breast cancer.

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