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 (Stratelsis, 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
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 (FEV₁) 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 from 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, FEV₁), 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 (FEV₁) 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.

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

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, FEV₁, 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.
References


