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Quality of life in chronic obstructive pulmonary disease and chronic heart failure : disease-specific and generic factors in adaption to illness

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disease-specific and generic factors in adaptation to illness

Rosemarie Arnold

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Paranimfen	Carolien Arnold Joost Keers

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Stellingen

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Quality of life in Chronic Obstructive Pulmonary Disease and Chronic Heart Failure: disease-specific and generic factors in adaptation to illness

Rosemarie Arnold, 20 september 2004

1 Ondanks de verschillen in kwaliteit van leven tussen patiënten met COPD en CHF, is de aanpassing aan beide ziekten vergelijkbaar.

2 Voor het voorspellen van de algemene gezondheidsbeleving van patiënten is het belangrijker om te weten welke fysieke beperkingen iemand ervaart, dan wat de medische ernst is van het onderliggende pulmonale en cardiale disfunctioneren.

3 Hoe meer domeinen van kwaliteit van leven zijn aangetast door een ziekte, des te groter is het effect op de algemene kwaliteit van leven van chronisch zieke patiënten.

4 Aandacht voor het verbeteren van percepties van controle bij het behandelen van patiënten met COPD en CHF leidt tot een verbetering van de kwaliteit van leven.

5 Het testen van theorieën is van groot belang voor de praktijk, oftewel: 'Nothing is as practical as a good theory!' (CREATE-workshop, EHPS conference, 2000)

6 De veronderstelling dat een hogere mate van persoonlijke controle is gerelateerd aan een hogere mate van welbevinden is gebaseerd op opvattingen vanuit de westerse cultuur.

7 Voor sommige mensen is leven een chronische aandoening.

8 Het toenemend individualisme in onze maatschappij wordt weerspiegeld in het onderwijs: tegenwoordig beginnen kinderen in het basisonderwijs niet meer met het leren van het woord 'aap' of 'boom', maar met het woord 'ik'.

9 Het begrip 'schone oorlog' is, net als 'milieuvriendelijke auto' en 'vegetarische hamburger', een contradictio in terminis.

10 De ervaring dat vaak niet het bereiken van de top, maar de weg ernaar toe het meeste de moeite waard is, plaatst het begrip 'topprestatie' in een heel ander daglicht.

11 Het feit dat het langdurig bespelen van hetzelfde muziekinstrument tot persoonlijkheidsveranderingen kan leiden, is voldoende reden om instrumenten met een bijsluiter te leveren.

12 Vertrouw nooit iets dat zelf denkt, terwijl je niet kunt ontdekken waar z'n verstand zit. (J.K. Rowling, 'Harry Potter and the Chamber of Secrets')

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De dag is haast voorbij
de top van de berg
kwam even in zicht

Willem Hussem

Contents

1

General introduction

As soon as a chronic illness is diagnosed, individuals become patients who will most likely be confronted with impairments in many areas of their lives. Often, patients experience the first symptoms accompanying their illnesses long before their diagnosis. Furthermore, illness development and progression will affect their physical functioning, which eventually leads to limitations in daily activities. Consequently, the ability to participate in normal social activities becomes restricted. Furthermore, the unpleasant symptoms and consequences of the disease, and the prospects of progressive limitations in the future, are also likely to affect the psychological well-being of the patients. During the course of their illness patients with chronic illnesses have to cope with the many consequences of their illness. This process, in which patients learn to deal with their limitations, can be interpreted as a process of adaptation to the illness.

This thesis addresses the process of adaptation in patients with Chronic Obstructive Pulmonary Disease (COPD) and in patients with Chronic Heart Failure (CHF), and investigates whether adaptation to these illnesses is a disease-specific process or generic. We chose to study these two disorders as they are not only highly prevalent but also chronic conditions. Furthermore, the clinical characteristics of both disorders are to a certain extent comparable. Over the last four years, the Epsylon (the Effects of Psychological factors on Long-term illness) study has been carried out to study whether patients with COPD and CHF differed from each other with respect to different aspects of their QoL. Furthermore, the psychological and medical factors that contributed to the quality of life of these groups of patients were investigated.

This introductory chapter provides a brief review of the causes and characteristics of COPD and CHF. In addition, it describes the consequences of both illnesses for the patients. A theoretical framework is then presented, in which the theories on which this study was based are discussed. Finally, the design of this study is addressed, followed by an overview of the chapters in this book.

Chronic Obstructive Pulmonary Disease

COPD refers to a 'set of conditions that develops progressively as a result of a number of different disease processes'[1]. COPD is characterised by airflow obstruction and a loss of pulmonary function that is not fully reversible by pharmacological treatment[2]. This airflow obstruction is progressive and is often accompanied by airway hyperresponsiveness to particles or gases[1]. Most patients with COPD experience symptoms such as chronic coughing, dyspnoea, production of sputum, and wheezing[3].

Prevalence and incidence

COPD is one of the most prevalent medical conditions worldwide[4] and forms an important cause of chronic morbidity and mortality[5]. COPD is the fourth leading cause of death worldwide,[6] and further increases in the prevalence and mortality of the disease are expected[4]. Since COPD is usually only diagnosed in its advanced stages, prevalence and mortality data underestimate the total burden of COPD. In 1990, the worldwide prevalence of COPD was estimated to be 9.34/1000 in men and 7.33/1000 in women[6]. However, these numbers include all ages and therefore may underestimate the prevalence of COPD in older adults. More recent research in European countries has indicated that approximately 4-6% of the adult population has COPD[7]. In the Netherlands, the prevalence of COPD was 24.3/1000 for men and 17.0/1000 for women in 2000. The incidence of COPD in 2000 in the Netherlands was 2.5/1000 for men and 2.0/1000 for women. Mortality caused by COPD was 49.0/100,000 for men and 29.2/100,000 for women in 2001 in the Netherlands[8].

Diagnosis

The diagnosis of COPD includes patients with chronic bronchitis and pulmonary emphysema and a small subgroup of patients with asthma. Chronic bronchitis is diagnosed when patients suffer from a chronic cough and the production of sputum lasting for more than three months in a year over two or more successive years[9]. Chronic inflammation of the airways of patients with chronic bronchitis causes scar tissue, which leads to fixed airway obstruction.

Pulmonary emphysema is caused by dilatation and destruction of the respiratory bronchioles. In mild emphysema, the lesions may be restricted to the upper parts of the lung, although in more advanced emphysema, the lesions may occur throughout the entire lung tissue[6]. In patients with emphysema, hyperinflation of the chest leads to increased lung volumes and decreased elasticity of the lung tissue, and eventually reduces the capacity of the respiratory muscles[9].

A diagnosis of COPD should be considered when patients suffer from coughing, sputum production, dyspnoea, or a history of exposure to risk factors for COPD. The diagnosis is confirmed by an objective measurement of airflow limitation, preferably by means of spirometry. Spirometry measures the maximum volume of air forcibly exhaled (forced vital capacity, FVC), and the volume of air exhaled during the first second of this assessment (forced expiratory volume in 1 second, FEV_1). Patients with COPD usually show a decrease in both FVC and FEV_1[6]. To rule out the diagnosis of asthma, reversibility of the airflow obstruction is tested by assessing lung function parameters before and after an adequate dose of inhaled bronchodilator[9].

Development and progression

Smoking is the most important contributing factor in the development of COPD worldwide[3]. The prevalence of lung function abnormalities and respiratory symptoms is higher in smokers than in non-smokers. Furthermore, the annual rate of decline in lung function is higher in smokers[6]. Cigarette smoking causes almost 90% of the cases of COPD, although it takes more than twenty pack-years (the number of pack-years indicates the number of years the patient smoked one pack of cigarettes a day) for COPD to develop. Approximately 10-15% of smokers develop COPD, which indicates the individual differences in susceptibility to the effects of smoking[9]. Other, less important risk factors for COPD are host factors, such as airway hyperresponsiveness, or environmental factors, such as occupational dust or air pollution[6].

In COPD patients, lung function continually deteriorates and FEV_1 values do not return to normal levels. As a result, patients with COPD experience a gradual deterioration in functional status, although the level of FEV_1 at which patients start to experience limitations is individually different. Moreover, patients with COPD increasingly experience dyspnoea – or shortness of breath – symptoms, which leads them to reduce their physical activities to avoid these symptoms. In turn, this decline in physical activity contributes to physical deconditioning, muscle weakness and a reduction in exercise tolerance[10]. The GOLD group has recommended a classification of disease severity into five stages[5]. Initially, (Stage 0) patients experience mild symptoms, while lung function is still normal. The first stage (mild COPD) is characterised by mild airflow limitation, whereas at stage 2 the airflow limitation is more severe ($FEV_1 < 80\%$ of predicted), which leads to the progression of symptoms and dyspnoea on exertion. In the third stage, lung function has further deteriorated (FEV_1 between 50% and 30% of predicted). Finally, stage 4 indicates very severe COPD with severe airflow limitation (FEV_1 lower than 30% of predicted) and the presence of chronic respiratory failure. At this stage, exacerbations may be life-threatening[6].

Treatment

The treatment of patients with COPD is mainly aimed at effective management of the disease[6]. This management is aimed at the prevention of disease progression, the reduction of mortality, and improvements with respect to symptoms, exercise tolerance, health status, complications, and exacerbations. Pharmacological treatment mainly consists of bronchodilators, corticosteroids, and antibiotics. Oxygen therapy is prescribed for patients in advanced stages of COPD. In cases of diffuse emphysema, lung volume reduction surgery is sometimes performed, though this procedure is not widely used. Furthermore, lung transplantation is occasionally performed in patients with very advanced COPD.

In addition to pharmacological treatment or medical interventions, pulmonary rehabilitation is an important component of the non-pharmacologic treatment of patients with COPD[6]. Pulmonary rehabilitation normally involves several types of health professionals. A comprehensive rehabilitation programme should consist of exercise training, nutrition counselling, and education[6]. Research has shown that COPD patients at all stages of the disease benefit from exercise training programmes, leading to improvements in exercise tolerance and symptoms of dyspnoea and fatigue[11-13]. Moreover, several studies have reported positive effects of pulmonary rehabilitation on the quality of life of the patients[14].

Chronic Heart Failure

Over the past twenty to thirty years, advances in diagnostic procedures, pharmacological treatment, and surgical techniques have contributed to a longer life expectancy for cardiac patients[15]. The improvement in the management of heart disease has not led to a cure, however, but rather resulted in an increasing number of patients surviving one or more myocardial infarctions, or other cardiac disease. Subsequently, an increasing number of patients develops a condition of chronic heart failure. There is a great deal of inconsistency in the definitions of heart failure[16], due to its multiple aetiological factors[17] and the lack of specific diagnostic criteria[16]. The American College of Cardiology/American Heart Association Task Force has defined heart failure as 'a complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to fill with or eject blood'. Manifestations of heart failure are dyspnoea and fatigue, which may lead to a reduced exercise capacity, and fluid retention, which may cause pulmonary congestion and peripheral oedema[18]. Since not all patients experience fluid retention at diagnosis, the term 'heart failure' is preferred over the older term 'congestive heart failure'[18]. In this thesis, we focused on patients with left ventricular systolic heart failure.

Prevalence and incidence

Chronic heart failure has been acknowledged as a common and growing public health problem in both developed and developing countries[19]. Relatively little is known about the exact prevalence and incidence of heart failure. Estimates of the prevalence and incidence of heart failure vary greatly across studies, caused by differences in definitions of heart failure and methodology rather than differences between populations[20]. Furthermore, heart failure is primarily a disease of the elderly[21], and therefore data on the prevalence of heart failure should be adjusted for age. During the 1980s, the Framingham heart study was performed, which has become one of the most important longitudinal sources of data on the epidemiology of heart failure[22;23]. This study revealed a prevalence of heart failure of 8/1000 for men and women under 60 years of age, and a prevalence of 66/1000 for men and 79/1000 for women over 80 years of age. A European study found a prevalence of heart failure of 170/1000 for men and 110/1000 for women over 75 years of age[24]. More recently, a study in the Netherlands reported prevalence estimates for patients between 75 and 85 years of 14.4% for men and 12.1% for women[25]. In 2000, the incidence of heart failure in the Netherlands was estimated to be 11.1/1000 for men and 9.0/1000 for women over 55 years of age. Mortality caused by heart failure in 2002 was 29.5/100,000 for men and 47.0/100,000 for women[26].

Diagnosis

Two types of failure of the left ventricle of a cardiac origin are discriminated. First, heart failure due to an impairment of left ventricular function, often in conjunction with a dilated heart chamber and reduced wall motion, which is indicated as systolic heart failure. The main characteristic of patients with systolic dysfunction is an impairment in the ejection of blood, detected by a diminished left ventricular ejection fraction. Ejection fraction values lower than 40% are normally used to indicate heart failure[18], although cut-off scores of 30%[27;28], 35%[16] or 45%[17;29] have also been used. In healthy people, ejection fraction values should be higher than 50%[30]. Second, patients with diastolic heart failure have normal left-ventricular emptying with an impairment of ventricular filling. Patients with systolic and diastolic heart failure require different treatment strategies. As the majority of patients with heart failure suffer from systolic heart failure[18], this is the group focused on in this study.

Heart failure is a clinical diagnosis and there is no 'gold standard' assessment tool to confirm the diagnosis[18;20]. A heart failure diagnosis should be considered when patients experience limitations in their exercise tolerance due to dyspnoea or fatigue, or both. These symptoms may occur during exercise or at rest. Furthermore, patients with heart failure may complain of leg or abdominal swelling caused by fluid retention. The echocardiogram is the most useful diagnostic test to determine the structural abnormality that causes heart failure. The primary aim of this assessment is to measure the left ventricular ejection fraction, which is an accurate indication of systolic dysfunction. Since it may not always be possible to determine the cause of heart failure, physicians usually focus on the clinical assessment of the patients[18]. Physicians inquire about the type and severity of symptoms that may impair patients' functional status. Usually, the New York Heart Association (NYHA) functional classification is used to determine the extent to which patients experience functional limitations. The NYHA functional class indicates the subjective experience of dyspnoea at rest and during exercise, progressing from I (no symptoms present), II (presence of symptoms during heavy exercise), III (presence of symptoms during gentle exercise), to IV (presence of symptoms at rest)[26].

Development and progression

Heart failure is the result of various disease processes that lead to reduced cardiac function[20]. Several risk factors for heart failure have been described[31], increasing age being the most important[21]. Furthermore, most patients with heart failure have a history of hypertension or coronary heart disease[21]. Valvular heart disease is a much less common cause of heart failure; the term 'idiopathic cardiomyopathy' is used when the cause of heart failure is unknown[18;20]. Relatively controllable risk factors for heart failure include hypertension, diabetes, cigarette smoking, obesity, a high total cholesterol to high density cholesterol ratio, and hematocrit levels (both high and low levels)[18;21].

The left ventricular dysfunction in patients with chronic heart failure is a progressive process that can be characterised by four stages. The first stage identifies patients at high risk of developing heart failure due to the presence of conditions associated with the development of heart failure, such as hypertension or coronary artery disease. The second stage indicates patients who have a structural disorder of the heart but have not developed symptoms of heart failure. The third stage refers to patients who have current or prior symptoms of heart failure (dyspnoea or fatigue) associated with underlying structural heart disease. Finally, in the last stage are patients with advanced structural heart disease, with symptoms of heart failure at rest, or patients who require specialised treatment strategies, such as heart transplantation[18]. Chronic heart failure is a serious disease with a poor prognosis, reducing the life-span of patients dramatically[31]. Earlier studies estimated survival rates about 60% one year after diagnosis, while five-year survival rates were 25% for men and 38% for women[32;33]. Recent research, however, has shown some improvement in the prognosis of heart failure since the early 1990s, although mortality rates after five years are still over 50% for men and women[34].

Treatment

The treatment of patients with heart failure is based on several components. First, primary prevention consists of the treatment of potential causes of heart failure (for instance, the treatment of ischemia or hypertension). Secondary prevention is aimed at the modulation of the progression of left ventricular dysfunction[35]. The management of chronic heart failure includes pharmacological and non-pharmacological treatment. Pharmacotherapy is of paramount importance in the treatment of chronic heart failure and primarily consists of Angiotensine Converting Enzyme(ACE)-inhibitors, Angiotensine-II inhibitors, diuretics, and beta-blockers. Furthermore, spironolactone and digoxin have been found to be important in the treatment of patients with heart failure[35].

The non-pharmacological treatment refers to general advice and measures concerning symptoms, weight control and health behaviours, such as refraining from smoking. In addition, cardiac rehabilitation is an important component of the non-pharmacological treatment of patients with heart failure[36;37]. Cardiac rehabilitation normally includes exercise training, relaxation instructions, psychological and dietary interventions (where necessary), and education and information concerning the disease and its treatment[38;39]. Previous research has found improvements in exercise capacity as a result of exercise training programmes for patients with heart failure[40;41]. Furthermore, the quality of life of patients with heart failure has been found to improve during rehabilitation[29;36]. Finally, in the treatment of end-stage heart failure, cardiac resynchronisation therapy or heart transplantation may be considered[35].

Theoretical framework

Psychological research into the effects of physical illness has mainly focused on the emotional and behavioural consequences of particular illnesses. The main area of interest is the adaptation of patients to the disease and its treatment, or their means of coping with the illness. When patients are confronted with a, in this case chronic, illness, they have to face many limitations to different aspects of their lives. These patients do not have the prospect of complete recovery and they will have to live with the limitations imposed by their illnesses. Moreover, patients are required to deal with the insecurity of not knowing what the course of their illness will be. In the case of patients with COPD and CHF, patients have to endure symptoms that will fluctuate but will eventually worsen as the illness develops. Moreover, the extent of impairment patients experience in performing the activities of daily life or social activities with friends or family will increase as a result of the illness's progress. The progression of symptoms and limitations, and the fact that their condition will not be cured, are likely to affect the patients' well-being. Therefore, psychological studies have generally assumed that the diagnosis of a chronic illness may well be an important 'life event' for the patients[42], or even a crisis[43] that engenders a certain amount of stress.

One of the factors that has been associated with adaptation to illness is personal control[44]. Personal control refers to individuals' belief in their capacity to exert control over their own lives[45;46]. In particular, personal control has been found to be related to health behaviour[47]. Several forms of personal control can be discriminated, including mastery, perceived health competence, and self-efficacy. Mastery is the extent to which people feel in control of the forces that affect their lives[48], and it has been associated with well-being and health[49;50]. Furthermore, mastery has been found to be negatively associated with functional decline[51]. Perceived health competence is another form of personal control that refers to control over one's health[52]. Previous research has shown that higher levels of perceived health competence were related to increased numbers of preventive health behaviours, such as engaging in physical exercise, abstinence from smoking, and weight maintenance[53]. A third form of personal control is self-efficacy, which concerns people's subjective estimation of their capacity for engaging in a particular action in a particular situation[54]. These perceptions of self-efficacy determine the courses of action people choose, how much effort they make to attain particular goals, and how long they will persist in the event of failure[55]. Self-efficacy has been found to be an important determinant of health promotive behaviours[56], such as smoking cessation[57], medication adherence[58], and physical exercise[59]. Since the various forms of personal control have been associated with well-being, physical functioning, and health promotive behaviours, perceptions of personal control are likely to be important factors in the process of adaptation to illness.

In contrast with psychological studies, clinical trials using the 'biomedical model' originally focused on the biological, physiological and clinical outcomes of disease and treatment[60]. In the last twenty to thirty years, the focus of clinical trials has gradually shifted towards a somewhat broader perspective. Part of this process was initiated by the World Health Organization (WHO), which adopted a new and broader definition of health as 'a state of complete physical, mental, and social well-being, and not merely the absence of disease'[61]. This definition of health, including mental and social well-being in addition to physical health, has stimulated the development of the concept of quality of life, thereby including the outcomes of disease as perceived by the patients in the health assessment[62].

Since the early 1960s, increasing interest in the assessment of quality of life has emerged[62;63]. A need for instruments to measure quality of life arose as a consequence of this increased interest in the concept. This increasing interest has resulted in rapid growth in the development of instruments to measure quality of life, beginning in the 1970s[62]. However, the growth of the number of quality of life instruments has led to controversy concerning the definition of quality of life and the dimensions of quality of life that can be discriminated[63]. Although the World Health Organization Quality of Life assessment (WHOQOL) group has had a guiding role in defining quality of life[64], to date no single definition of quality of life has been generally accepted[65-68].

Various conceptualisations of quality of life have been used, ranging from general to more specific[69]. General definitions refer to quality of life as the perception of life in general, whereas health-related quality of life denotes life quality insofar as it is related to aspects of health. The term 'health-related quality of life' has been used for disease-specific limitations and for more generic health-related problems[70]. Disagreement concerning dimensions, definition, and measurement of quality of life has resulted in a vast number of theories, models, and frameworks, many of which are described by Taillefer et al.[63]. Two of them are of major importance to our study, namely Spilker's hierarchical model of quality of life[71;72], and Wilson and Cleary's conceptual model of patient outcomes[60] (see Figure 1.1).

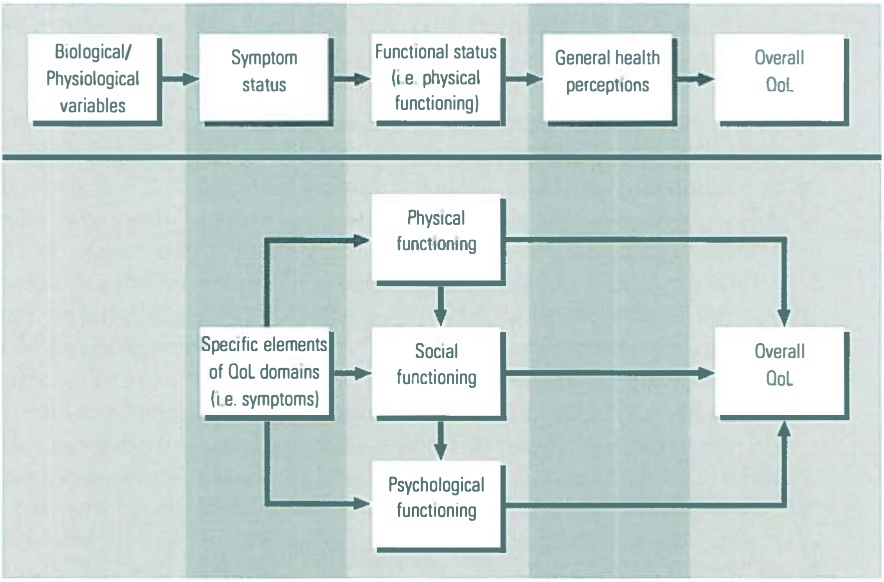

Figure 1.1 Theoretical models of Wilson & Cleary[60] (above) and Spilker[71;72] (below)

Wilson and Cleary's model[60] is of major importance as it integrates the biomedical and social scientific model. Wilson and Cleary organise different measures of health from biological factors at one end of the continuum to quality of life at the other. Moreover, this model assumes specific causal relationships between the different health concepts, without reciprocal effects[73]. The five levels in the model, representing different health concepts, are (1) biological and physiological variables, (2) symptom status, (3) functional status, (4) general health perceptions, and (5) overall quality of life. Wilson and Cleary's model is a very suitable model to study the interplay between medical and psychological aspects of health.

Current study

Research questions & background of the study

The models discussed above in the theoretical framework were used as the basis of our research and guided decisions concerning the research questions and, consequently, the variables of interest in this study. The two main research questions in this thesis were (1) do patients with COPD and CHF differ from each other with respect to their adaptation to the illness? (2) do medical and psychological factors contribute to the adaptation of patients with COPD and CHF? In this thesis, the focus was on the outcomes of the adaptation process to study the quality of life of the patients with either COPD or CHF.

The main aim of this research was to investigate whether adaptation to illness is a process, specific for each illness, or rather a generic process. Only a few previous studies have compared different illnesses with respect to psychological adaptation and the quality of life of the patients[74-84]. Some studies have reported differences between disorders with respect to domains of quality of life[76;78-84]. Most of these studies indicate that patients with chronic medical conditions differ from healthy people with respect to physical aspects of quality of life[76;78;80;81]. The effects of medical conditions on psychological functioning are less consistent: some studies reveal differences in psychological functioning between patients with chronic disorders and healthy people[76;78;79]. In contrast, other studies did not report differences in psychological functioning between chronically ill patients and healthy subjects[74;80]. These studies indicate that research is still needed to elucidate the effects of different chronic disorders on the quality of life of the patients.

In this study, we chose to compare patients with COPD and CHF for various reasons. First, scant literature is available concerning the differences in the process of adaptation between patients with different diseases. We tried not to vary too many factors at once by studying comparable illnesses in order to thoroughly map the illness-specific and generic factors in the adaptation to these illnesses. We deemed COPD and CHF to be comparable since both are prevalent diseases and are important causes of death worldwide. Second, both illnesses have a considerable impact on the physical functioning of the patients and are progressively developing illnesses. Furthermore, both COPD and CHF are characterised by breathlessness and a reduced exercise capacity, and both illnesses are to a certain extent related to unhealthy habits, such as smoking. However, despite the similarities between both illnesses, the underlying causes of both illnesses are quite different and, therefore, differences may exist in the extent to which QoL domains are affected. Moreover, we studied whether there were any differences in the psychological and medical factors related to the QoL of patients with COPD and CHF.

Design

To assess the effects of COPD and CHF for a wide range of patients, we recruited patients in different treatment settings. First, we recruited patients with COPD and CHF who had been referred to a rehabilitation centre. For both groups of patients this was a multidisciplinary programme, which included exercise training, dietary interventions, and education. Second, prevalent patients with COPD and CHF who received usual care in an outpatient clinic were included in this study. We were thereby able to compare changes in QoL during rehabilitation with a reference group from the population in the outpatient clinic.

This study consisted of two assessments. Patients with COPD or CHF in rehabilitation were evaluated both before and after they participated in the rehabilitation programme. The average length of pulmonary rehabilitation was twenty weeks; the duration of cardiac rehabilitation, on the other hand, was eight weeks on average. Patients with COPD and CHF in the outpatient clinics were assessed at intervals of four months, which was determined to be the average of the duration of pulmonary and cardiac rehabilitation. Consecutive patients were recruited from January 2001 through June 2002.

Patients

The criteria for inclusion in the study for patients with COPD were (1) diagnosed with COPD, (2) registered with a forced expiratory volume in 1 second (FEV_1) less than 70% of the predicted value, and (3) free from other pulmonary disease. For patients with CHF the criteria for inclusion were (1) diagnosed with CHF and (2) registered with a left ventricular ejection fraction (LVEF) less than 45%. Patients with CHF were excluded if they suffered from angina pectoris or atrium fibrillation, if they had had heart transplant surgery, or if they had recently (in the year preceding enrolment in the study) had a myocardial infarction. Both patients with COPD and patients with CHF were aged between 40 and 80 years old, free from serious co-morbidity (such as cancer), free from psychiatric problems in the previous year, and fluent in the Dutch language. A total of 110 patients with COPD were included in this study, i.e. 54 patients in rehabilitation and 56 patients in the outpatient clinics of a university hospital and a general hospital. With respect to CHF, 94 patients were included in the study, i.e. 29 patients in rehabilitation and 65 patients in the outpatient clinic of the University Hospital.

In order to study the adaptation of the patients to COPD and CHF, we assessed several physical and psychosocial variables by means of self-report mailed questionnaires. These variables included quality of life (overall QoL as well as QoL domains), illness-specific symptoms, and personal control (mastery, perceived health competence, self-efficacy). Furthermore, data on clinical characteristics were collected from the patients' medical records. In the group of patients with COPD, we collected data on lung function parameters (FEV_1 in litres, FEV_1%pred and FVC in litres); for the patients with CHF, information on left ventricular dysfunction (LVEF) and New York Heart Association (NYHA) functional class was collected. Illness duration was assessed in both patient groups.

Overview

This thesis has been divided into two separate parts. Since previous research has shown that perceptions of personal control are associated with adaptation to illness[44] and these perceptions of control are important determinants of the QoL and well-being of chronically ill patients[45], the relationships between several aspects of personal control and QoL of patients with COPD and CHF are explored in the first part of this book. *Chapter 2* studies the changes during rehabilitation in patients with COPD with respect to perceptions of personal control, while *Chapter 3* is concerned with the relationship between perceptions of personal control and the physical domain of QoL in patients with COPD as well as patients with CHF. The second part of this thesis concerns more theoretical studies of the concept of QoL, health, and the different underlying aspects of health. This part of the thesis is based on two different theoretical models. First, Spilker's hierarchical model of QoL[71;72] is explored in patients with different chronic diseases in *Chapter 4* and, subsequently, this model was tested in patients with COPD and CHF in *Chapter 5*. Second, Wilson & Cleary's conceptual model of health outcomes[60] was tested in *Chapter 6*, through a study of the relationship between objective and subjective health parameters.

First part

In *Chapter 2* we studied whether perceptions of mastery and self-efficacy were related to better outcomes of pulmonary rehabilitation in patients with COPD. For rehabilitation to be successful, patients often need to accomplish certain changes in their behaviour. Smoking, for example, is the most important contributing factor in the development and progression of COPD[3;85], which many patients find hard to change. Previous research has revealed that COPD patients referred for rehabilitation had often lost their motivation[86]. Moreover, failed efforts to change their behaviour may result in decreases in their perceptions of control. Consequently, the treatment of patients with COPD may be rather difficult, as part of its effects depends on patients' efforts to engage in healthy behaviours, such as to abstain from smoking or to engage in physical exercise. Perceptions of personal control may be important factors related to the effects of rehabilitation[57;87-89], since these perceptions influence patients' motivation to make the required efforts during rehabilitation. Therefore, we first examined whether QoL and perceptions of mastery and self-efficacy improved in patients with COPD who were referred to a rehabilitation programme, and compared these patients with a reference group of COPD patients from the outpatient clinic of a general hospital who received usual care. Second, we studied whether increased perceptions of mastery and self-efficacy contributed to a higher level of QoL after rehabilitation.

Chapter 3 presents the results regarding the relationship between self-efficacy and the physical domain of QoL in patients with COPD and CHF. With respect to clinical characteristics, COPD and CHF are readily comparable: both are progressive illnesses, characterised by breathlessness and a diminished exercise capacity[90]. Although patients with COPD and CHF experience comparable limitations, differences between the diseases may exist in the extent to which QoL domains are affected, since for both COPD and CHF the underlying causes of the functional limitations are quite different. However, the factors that contribute to QoL in COPD and CHF may be comparable in that the processes through which QoL is affected may be comparable for COPD and CHF. Therefore, patients with COPD and CHF were compared with respect to QoL domains and perceptions of personal control. Moreover, it was examined whether self-reported physical functioning of patients with COPD and CHF was primarily explained by illness-specific differences related to diagnosis, or whether more generic factors, such as illness severity and perceptions of self-efficacy, also contributed to physical functioning.

Second part

Chapter 4 focuses on the relationship between domains of QoL and overall QoL in patients with eight different chronic diseases. Despite the growing interest in clinical and social scientific studies in the assessment of the QoL of chronically ill patients, there is no uniform definition of QoL[66]. In this chapter, we used Spilker's hierarchical QoL model[71;72] to study the relationship between QoL domains and overall QoL in different groups of patients. More specifically, we studied whether the physical, social and psychological QoL domains contributed differentially to overall QoL. Furthermore, we investigated to what extent these domains together explained overall QoL. As a result of disease-specific factors such as specific symptoms or limitations, different medical conditions may have a differential impact on the QoL domains of the patients and, consequently, the relationship between QoL domains and overall QoL may vary between disorders. Therefore, we studied the relationship between QoL domains and overall QoL in eight different disease groups. The data described in this chapter were not a part of the Epsylon study but were collected as part of the Groningen Longitudinal Aging Study (GLAS).

In *Chapter 5* we focussed further in on Spilker's hierarchical QoL model[71;72] and added the third level of his model to our study. This means that we studied QoL at the overall level of life quality, at the level of the physical, social, and psychological functioning domains, and at the level of the underlying aspects of QoL domains. In particular, we assessed the relationship of symptoms of dyspnoea, interpreted as a specific aspect of the physical domain of QoL, with QoL domains and overall QoL in patients with COPD and CHF. We chose symptoms of dyspnoea to represent the third level of Spilker's model (i.e. specific aspects of QoL domains), since these symptoms are important characteristics of COPD as well as CHF. Moreover, we tested this model by means of structural equation modelling. Thus, we investigated two research questions. First, we studied whether symptoms of dyspnoea affected overall QoL through the physical, social, and psychological QoL domains. Second, we studied whether this relationship between dyspnoea and overall QoL was similar for patients with COPD and patients with CHF. Furthermore, we hypothesised a hierarchical ordering among the QoL domains at level 2 of Spilker's model, that is, we hypothesised that the physical domain of QoL affected overall QoL through the social and psychological domains.

Finally, in *Chapter 6*, we used a more extensive model of health, originally developed by Wilson and Cleary[60]. We chose to study this model since it incorporates both objective physical health indicators as well as more subjective health factors, such as perceived health and overall QoL (see Figure 1.1). This model thereby integrates the biomedical model used in clinical studies with the social scientific perspective adopted in psychological studies. The aim of this study was to investigate the relationship between objective and subjective health parameters in patients with COPD and in patients with CHF. Particular attention was paid to whether the relationship between objective health parameters (FEV_1 for COPD and LVEF for CHF) and general health perceptions was mediated by symptoms of dyspnoea and physical functioning. Furthermore, we studied whether perceptions of personal control were related to the health parameters in our model. We tested the relationships between the health parameters in the model by means of structural equation modelling. Although the underlying causes of COPD and CHF are quite different, we hypothesised that the processes through which the different aspects of health affect each other may be comparable for patients with COPD and CHF.

Chapter 7 presents a summary and general discussion of the main results and implications of these findings. Finally, this thesis ends with a brief summary of the results.

Reference List

1 Mannino DM. COPD: epidemiology, prevalence, morbidity and mortality, and disease heterogeneity. Chest 2002; 121: 121S-126S.

2 American Thoracic Society. Standards for the diagnosis and care of patients with chronic obstructive pulmonary disease. Am J Respir Crit Care Med 1995; 152: S77-121.

3 Rennard SI. COPD: overview of definitions, epidemiology, and factors influencing its development. Chest 1998; 113: 235S-241S.

4 Murray CJ, Lopez AD. Alternative projections of mortality and disability by cause 1990-2020: Global Burden of Disease Study. Lancet 1997; 349: 1498-1504.

5 Pauwels RA, Buist AS, Ma P, Jenkins CR, Hurd SS. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. National Heart, Lung, and Blood Institute and World Health Organization Global Initiative for Chronic Obstructive Lung Disease (GOLD): executive summary. Respir Care 2001; 46: 798-825.

6 Global Initiative for Chronic Obstructive Lung Disease. Global strategy for the diagnosis, management, and prevention of Chronic Obstructive Pulmonary Disease. NHLBI/WHO workshop report. Update of the management sections. National Heart, Lung and Blood Institute. 2003 Jul 1 [cited 2004 Mar 4] Available from: http://www.goldcopd.com.

7 Gulsvik A. Mortality in and prevalence of chronic obstructive pulmonary disease in different parts of Europe. Monaldi Arch Chest Dis 1999; 54: 160-162.

8 Boezen HM, Postma DS, Smit HA, Gijsen R, Poos MJJC. Hoe vaak komen astma en COPD voor en hoeveel mensen sterven eraan? RIVM. Volksgezondheid Toekomst Verkenning,

Nationaal Kompas Volksgezondheid. 2003 Sep 15 [cited 2004 Mar 3] Available from: http://www.nationaalkompas.nl.

9 Kaptein AA, Scharloo M. Chronic Obstructive Pulmonary Disease: a behavioural medicine approach. In: Llewelyn S, Kennedy P, eds. Handbook of Clinical Health Psychology. Chichester: Wiley, 2003: 155-179.

10 Maltais F, LeBlanc P, Jobin J, Casaburi R. Peripheral muscle dysfunction in chronic obstructive pulmonary disease. Clin Chest Med 2000; 21: 665-677.

11 Lareau SC, ZuWallack R, Carlin B, Celli B, Fahy B, Gosselink R, Jones P, Larson JL, Meek P, Rochester C, Sassi-Dambron D, Stubbing D. Pulmonary rehabilitation-1999. American Thoracic Society. Am J Respir Crit Care Med 1999; 159: 1666-1682.

12 Berry MJ, Rejeski WJ, Adair NE, Zaccaro D. Exercise rehabilitation and chronic obstructive pulmonary disease stage. Am J Respir Crit Care Med 1999; 160: 1248-1253.

13 Ries AL, Kaplan RM, Limberg TM, Prewitt LM. Effects of pulmonary rehabilitation on physiologic and psychosocial outcomes in patients with chronic obstructive pulmonary disease. Ann Intern Med 1995; 122: 823-832.

14 Goldstein RS, Gort EH, Stubbing D, Avendano MA, Guyatt GH. Randomised controlled trial of respiratory rehabilitation. Lancet 1994; 344: 1394-1397.

15 Linden W. Cardiac conditions. In: Llewelyn S, Kennedy P, eds. Handbook of Clinical Health Psychology. Chichester: Wiley, 2003: 81-101.

16 Purcell IF, Poole-Wilson PA. Heart failure: why and how to define it? Eur J Heart Fail 1999; 1: 7-10.

17 Tavazzi L. Towards a more precise definition of heart failure aetiology. Eur Heart J 2001; 22: 192-195.

18 Hunt SA, Baker DW, Chin MH, Cinquegrani MP, Feldman AM, Francis GS, Ganiats TG, Goldstein S, Gregoratos G, Jessup ML, Noble RJ, Packer M, Silver MA, Stevenson LW. ACC/AHA guidelines for the evaluation and management of chronic heart failure in the adult: a report of the American College of Cardiology/American Heart Association task force on practice guidelines (committee to revise the 1995 guidelines for the evaluation and management of heart failure). American College of Cardiology Website. 2001. [cited 2004 Mar 5] Available from: http://www.acc.org/clinical/guidelines/failure/hf_index.htm.

19 McMurray JJ, Petrie MC, Murdoch DR, Davie AP. Clinical epidemiology of heart failure: public and private health burden. Eur Heart J 1998; 19 Suppl P: 9-16.

20 Cowie MR, Mosterd A, Wood DA, Deckers JW, Poole WP, Sutton GC, Grobbee DE. The epidemiology of heart failure. Eur Heart J 1997; 18: 208-225.

21 Kannel WB, Belanger AJ. Epidemiology of heart failure. Am Heart J 1991; 121: 951-957.

22 Davis RC, Hobbs FD, Lip GY. ABC of heart failure. History and epidemiology. BMJ 2000; 320: 39-42.

23 Ho KK, Pinsky JL, Kannel WB, Levy D. The epidemiology of heart failure: the Framingham Study. J Am Coll Cardiol 1993; 22: 6A-13A.

24 Landahl S, Svanborg A, Astrand K. Heart volume and the prevalence of certain common cardiovascular disorders at 70 and 75 years of age. Eur Heart J 1984; 5: 326-331.

25 Mosterd A, Hoes AW, de Bruyne MC, Deckers JW, Linker DT, Hofman A, Grobbee DE. Prevalence of heart failure and left ventricular dysfunction in the general population; The Rotterdam Study. Eur Heart J 1999; 20: 447-455.

26 Hoes AW, Mosterd A, Gijsen R, Poos MJJC. Hoe vaak komt hartfalen voor en hoeveel mensen sterven eraan? RIVM. Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. 2004 Feb 2 [cited 2004 Mar 3] Available from: http://www.nationaalkompas.nl.

27 Priori SG, Aliot E, Blomstrom-Lundqvist C, Bossaert L, Breithardt G, Brugada P, Camm JA, Cappato R, Cobbe SM, Di Mario C, Maron BJ, McKenna WJ, Pedersen AK, Ravens U, Schwartz PJ, Trusz-Gluza M, Vardas P, Wellens HJ, Zipes DP. Update of the guidelines on sudden cardiac death of the European Society of Cardiology. Eur Heart J 2003; 24: 13-15.

28 Brodie BR, Stuckey TD, Hansen C, Muncy D. Intra-aortic balloon counterpulsation before primary percutaneous transluminal coronary angioplasty reduces catheterization laboratory events in high-risk patients with acute myocardial infarction. Am J Cardiol 1999; 84: 18-23.

29 Willenheimer R, Erhardt L, Cline C, Rydberg E, Israelsson B. Exercise training in heart failure improves quality of life and exercise capacity. Eur Heart J 1998; 19: 774-781.

30 Marantz PR, Tobin JN, Wassertheil-Smoller S, Steingart RM, Wexler JP, Budner N, Lloyd Lense MPH, Wachspress J. The relationship between left ventricular systolic function and congestive heart failure diagnosed by clinical criteria. Circulation 1988; 77: 607-612.

31 Deedwania PC. Prevalence and prognosis of heart failure. Cardiol Clin 1994; 12: 1-8.

32 Ho KK, Anderson KM, Kannel WB, Grossman W, Levy D. Survival after the onset of congestive heart failure in Framingham Heart Study subjects. Circulation 1993; 88: 107-115.

33 Cowie MR, Fox KF, Wood DA, Metcalfe C, Thompson SG, Coats AJ, Poole-Wilson PA, Sutton GC. Hospitalization of patients with heart failure: a population-based study. Eur Heart J 2002; 23: 877-885.

34 Levy D, Kenchaiah S, Larson MG, Benjamin EJ, Kupka MJ, Ho KK, Murabito JM, Vasan RS. Long-term trends in the incidence of and survival with heart failure. N Engl J Med 2002; 347: 1397-1402.

35 Remme WJ, Swedberg K. Guidelines for the diagnosis and treatment of chronic heart failure. Eur Heart J 2001; 22: 1527-1560.

36 Pina IL, Apstein CS, Balady GJ, Belardinelli R, Chaitman BR, Duscha BD, Fletcher BJ, Fleg JL, Myers JN, Sullivan MJ. Exercise and heart failure: a statement from the American Heart Association Committee on exercise, rehabilitation, and prevention. Circulation 2003; 107: 1210-1225.

37 Colonna P, Sorino M, D'Agostino C, Bovenzi F, De Luca L, Arrigo F, de Luca I. Nonpharmacologic care of heart failure: counseling, dietary restriction, rehabilitation, treatment of sleep apnea, and ultrafiltration. Am J Cardiol 2003; 91: 41F-50F.

38 Berkhuysen MA, Nieuwland W, Buunk BP, Sanderman R, Rispens P. Change in self-efficacy during cardiac rehabilitation and the role of perceived overprotectiveness. Patient Educ Couns 1999; 38: 21-32.

39 Senten MCM, Kruijssen HACM, Hellemans IM. Hartrevalidatie: de stand van zaken in Nederland. Hartbulletin 1995; 27: 88-92.

40 Curnier D, Galinier M, Pathak A, Fourcade J, Bousquet M, Senard JM, Fauvel JM, Bounhoure JP, Montastruc JL. Rehabilitation of patients with congestive heart failure with or without beta-blockade therapy. J Card Fail 2001; 7: 241-248.

41 McKelvie RS, Teo KK, Roberts R, McCartney N, Humen D, Montague T, Hendrican K, Yusuf S. Effects of exercise training in patients with heart failure: the Exercise Rehabilitation Trial (EXERT). Am Heart J 2002; 144: 23-30.
42 De Ridder D, Schreurs K. Coping, social support and chronic disease: a research agenda. Psychology, Health and Medicine 1996; Vol 1: 71-82.
43 Moos RH, Schaefer JA. The crisis of physical illness. An overview and conceptual approach. In: Moos RH, ed. Coping with physical illness 2: new perspectives. New York: Plenum Medical Book Company, 1984: 3-25.
44 Moos RH, Schaefer JA. Coping resources and processes: current concepts and measures. In: Goldberger L, Breznitz S, eds. Handbook of stress: theoretical and clinical aspects (2nd ed.). New York, NY, Free Press, 1993: 234-257.
45 Skinner EA. A guide to constructs of control. J Pers Soc Psychol 1996; 71: 549-570.
46 Gurin P, Gurin G, Morrison BM. Personal and ideological aspects of internal and external control. Soc Psychol 1978; 41: 275-296.
47 Wallston KA. Perceived control and health behaviour. In: Baum A, Newman S, Weinman J, West R, McManus C, eds. Cambridge handbook of psychology, health and medicine. Cambridge: Cambridge University Press, 1997: 151-154.
48 Pearlin LI, Lieberman MA, Menaghan EG, Mullan JT. The stress process. J Health Soc Behav 1981; 22: 337-356.
49 Lachman ME, Weaver SL. The sense of control as a moderator of social class differences in health and well-being. J Pers Soc Psychol 1998; 74: 763-773.
50 Kempen GIJM, Jelicic M, Ormel J. Personality, chronic medical morbidity, and health-related quality of life among older persons. Health Psychol 1997; 16: 539-546.
51 Kempen GIJM, Sanderman R, Miedema I, Meyboom-de Jong B, Ormel J. Functional decline after congestive heart failure and acute myocardial infarction and the impact of psychological attributes. A prospective study. Qual Life Res 2000; 9: 439-450.
52 Smith MS, Wallston K, Smith C. The development and validation of the Perceived Health Competence Scale. Health Educ Res 1995; 10: 51-64.
53 Gebhardt WA, van der Doef MP, Paul LB. The Revised Health Hardiness Inventory (RRHI-24): psychometric properties and relationship with self-reported health and health behavior in two Dutch samples. Health Educ Res 2001; 16: 579-592.
54 Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 1977; 84: 191-215.
55 Bandura A. Self-efficacy and health behaviour. In: Baum A, Newman S, Weinman J, West R, McManus C, eds. Cambridge Handbook of Psychology, Health and Medicine. Cambridge: Cambridge University Press, 1997: 160-162.
56 Schwarzer R. Self-efficacy in the adoption and maintenance of health behaviors: theoretical approaches and a new model. In: Schwarzer R, ed. Self-efficacy: thought control of action. Washington, DC: Hemisphere Publishing Corp., 1992: 217-243.
57 Meland E, Maeland JG, Laerum E. The importance of self-efficacy in cardiovascular risk factor change. Scand J Public Health 1999; 27: 11-17.
58 Gifford AL, Bormann JE, Shively MJ, Wright BC, Richman DD, Bozzette SA. Predictors of self-reported adherence and plasma HIV concentrations in patients on multidrug antiretroviral regimens. J Acquir Immune Defic Syndr 2000; 23: 386-395.

59 Lox CL, Freehill AJ. Impact of pulmonary rehabilitation on self-efficacy, quality of life, and exercise tolerance. Rehab Psychol 1999; 44: 208-221.
60 Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA 1995; 273: 59-65.
61 World Health Organization. The first ten years of the World Health Organization. Geneva: World Health Organization, 1958.
62 Wood-Dauphinee SL. Assessment of back-related quality of life: the continuing challenge. Spine 2001; 26: 857-861.
63 Taillefer MC, Dupuis G, Roberge MA, Le May S. Health-related quality of life models: systematic review of the literature. Soc Indic Res 2003; 64: 293-323.
64 Kuyken W, Orley J, Power M, Herrman H, Schofield H, Murphy B, Metelko Z, Szabo S, Pibernik-Okanovic M. The world health organization Quality of Life assessment (WHOQOL): position paper from the world health organization. Soc Sci Med 1995; 41: 1403-1409.
65 Schipper H, Clinch J, Powell V. Definitions and conceptual issues. In: Spilker B, ed. Quality of life assessments in clinical trials. New York: Raven Press, 1990: 11-24.
66 Rogerson RJ. Environmental and health-related quality of life: conceptual and methodological similarities. Soc Sci Med 1995; 41: 1373-1382.
67 Leventhal H, Colman S. Quality of life: a process view. Psychol Health 1997; 12: 753-767.
68 Hunt SM. The problem of quality of life [editorial]. Qual Life Res 1997; 6: 205-212.
69 Suurmeijer TPBM, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. Epilepsia 2001; 42: 1160-1168.
70 Frisch MB. Improving mental and physical health care through quality of life therapy and assessment. In: Diener E, Rahtz DR, eds. Advances in quality of life theory and research. Boston: Kluwer Academic Publishers, 2000: 207-241.
71 Spilker B. Introduction to the field of quality of life trials. In: Spilker B, ed. Quality of life assessments in clinical trials. New York: Raven Press, 1990: 3-10.
72 Spilker B, Revicki D. Taxonomy of quality of life. In: Spilker B, ed. Quality of life and pharmacoeconomics in clinical trials. Philadelphia: Lippincott-Raven Publishers, 1996: 25-31.
73 Sullivan MD, Kempen GIJM, Van Sonderen FLP, Ormel J. Models of health-related quality of life in a population of community-dwelling Dutch elderly. Qual Life Res 2000; 9: 801-810.
74 Cassileth BR, Lusk EJ, Strouse TB, Miller DS, Brown LL, Cross PA, Tenaglia AN. Psychosocial status in chronic illness: a comparative analysis of six diagnostic groups. N Engl J Med 1984; 311: 506-511.
75 Felton BJ, Revenson TA, Hinrichsen GA. Stress and coping in the explanation of psychological adjustment among chronically ill adults. Soc Sci Med 1984; 18: 889-898.
76 Stewart AL, Greenfield S, Hays RD, Wells K, Rogers WH, Berry SD, McGlynn EA, Ware JE. Functional status and well-being of patients with chronic conditions: results from the Medical Outcomes Study. JAMA 1989; 262: 907-913.
77 Pollock SE, Christian BJ, Sands D. Responses to chronic illness: analysis of psychological and physiological adaptation. Nurs Res 1990; 39: 300-304.
78 Kempen GIJM, Ormel J, Brilman EI, Relyveld J. Adaptive responses among Dutch elderly: the impact of eight chronic medical conditions on health-related quality of life. Am J Public Health 1997; 87: 38-44.

79 Lisspers J, Nygren A, Söderman E. Psychological patterns in patients with coronary heart disease, chronic pain and respiratory disorder. Scand J Caring Sci 1998; 12: 25-31.

80 Schlenk EA, Erlen JA, Dunbar Jacob J, McDowell J, Engberg S, Sereika SM, Rohay JM, Bernier MJ. Health-related quality of life in chronic disorders: a comparison across studies using the MOS SF-36. Qual Life Res 1998; 7: 57-65.

81 Wirnsberger RM, De Vries J, Jansen TL, Van Heck GL, Wouters EF, Drent M. Impairment of quality of life: rheumatoid arthritis versus sarcoidosis. Neth J Med 1999; 54: 86-95.

82 Sprangers AG, De Regt EB, Andries F, Van Agt HME, Bijl RV, De Boer JB, Foets M, Hoeymans N, Jacobs AE, Kempen GIJM, Miedema HS, Tijhuis MAR, De Haes HCJM. Which chronic conditions are associated with better or poorer quality of life? J Clin Epidemiol 2000; 53: 895-907.

83 Stavem K, Lossius MI, Kvien TK, Guldvog B. The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. Qual Life Res 2000; 9: 865-871.

84 McEntee DJ, Badenhop DT. Quality of life comparisons: gender and population differences in cardiopulmonary rehabilitation. Heart Lung 2000; 29: 340-347.

85 Anthonisen NR, Connett JE, Murray RP. Smoking and lung function of Lung Health Study participants after 11 years. Am J Respir Crit Care Med 2002; 166: 675-679.

86 Büchi S, Wolf C, Schwarz F, Villiger B, Buddeberg C. Sind stationäre Rehabilitationsbehandlungen bei Patienten mit chronisch obstruktiver Lungenkrankheit (COLK) sinnvoll? Ergebnisse einer prospektiven 1-Jahres-Verlaufsstudie. Psychother Psychosom Med Psychol 1996; 46: 423-429.

87 Büchi S, Villiger B, Sensky T, Schwarz F, Wolf C, Buddeberg C. Psychosocial predictors of long-term success of in-patient pulmonary rehabilitation of patients with COPD. Eur Respir J 1997; 10: 1272-1277.

88 Ketelaars CA, Schlosser MA, Mostert R, Huyer-Abu-Saad H, Halfens RJ, Wouters EF. Determinants of health-related quality of life in patients with chronic obstructive pulmonary disease. Thorax 1996; 51: 39-43.

89 McCathie HCF, Spence SH, Tate RL. Adjustment to chronic obstructive pulmonary disease: the importance of psychological factors. Eur Respir J 2002; 19: 47-53.

90 Hamilton AL, Killian KJ, Summers E, Jones NL. Muscle strength, symptom intensity, and exercise capacity in patients with cardiorespiratory disorders. Am J Respir Crit Care Med 1995; 152: 2021-2031.

2

Changes in personal control as a predictor of quality of life after pulmonary rehabilitation

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Abstract

Objective

Perceptions of mastery and self-efficacy may be related to better outcomes in pulmonary rehabilitation in patients with Chronic Obstructive Pulmonary Disease (COPD). This study examined (1) whether the patients improved during a rehabilitation programme with respect to quality of life (QoL) and perceptions of self-efficacy and mastery, and (2) whether increased perceptions of mastery and self-efficacy contributed to a higher QoL after rehabilitation.

Methods

Thirty-nine consecutive patients (aged 60.5 ± 9.0) were included from a rehabilitation centre and were compared with 44 reference patients (aged 68.0 ± 8.2) with COPD in a general hospital.

Results

COPD patients improved during rehabilitation in overall QoL and self-efficacy, although no significant changes were found in QoL domains and mastery. The reference group did not change significantly with respect to any of the variables. Changes in self-efficacy during rehabilitation contributed to the explanation of the social and psychological functioning QoL domains, suggesting the importance of personal control in the adjustment to COPD.

Submitted

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is one of the main causes of disability in persons over 40[1]. COPD is characterised by a progressive airflow obstruction and a loss of pulmonary function[2]. Most patients with COPD experience symptoms such as a chronic cough, dyspnoea and the production of sputum[3]. The diagnosis of COPD includes patients with chronic bronchitis, characterised by a fixed obstruction of the airways, and pulmonary emphysema, caused by a decreased elasticity of the lung tissue. COPD has a serious impact on the quality of life (QoL) of patients[4], for example, most patients with COPD experience physical limitations as well as psychological problems, such as feelings of anxiety or depression[5].

Since COPD is an incurable disease, the treatment of patients with COPD is mainly aimed at effective disease management focused on the prevention of disease progression and on improvements with respect to symptoms and exercise tolerance[6]. In addition to pharmacological treatment, in the more severely affected patients pulmonary rehabilitation is recommended to support the management of COPD[1]. A comprehensive rehabilitation programme should consist of exercise training, nutrition counselling, and education[6]. Patients at all stages of COPD may benefit from exercise training (aerobic exercise and respiratory muscle strength training) during rehabilitation, leading to improvements in exercise tolerance and symptoms of dyspnoea and fatigue[7-9]. Pulmonary rehabilitation is particularly indicated in the more severely impaired patients with COPD, given the multidisciplinary approach of the programmes targeted at both pulmonary and non-pulmonary problems, and the improvement of QoL[6].

The treatment of patients with COPD may be rather strenuous since part of its effects depends on the patients' efforts to engage in certain healthy behaviours. For rehabilitation to be successful, patients need to accomplish changes in their behaviour, like stopping smoking or doing more physical exercise. Mostly, these are unhealthy behaviours the patients have engaged in for many years and therefore these behaviours are resistant to change. For example, smoking is the most important contributing factor in the development and progression of COPD[3;10], and is an unhealthy behaviour most patients find very hard to change. Therefore, it is very important for the patients to be motivated and committed to the rehabilitation programme to be able to accomplish changes in their behaviour. Many COPD patients referred for rehabilitation, however, face multiple and often complex problems, both physical and psychosocial[7]. Previous research has shown that COPD patients referred for rehabilitation had often lost their motivation to improve[11]. Moreover, repeated failed efforts to change their behaviour may have resulted in decreases in their perceptions of personal control[12-14].

Personal control refers to individuals' belief about their capacity to exert control over their own lives[15;16] and can be divided into several forms of control, including self-efficacy and mastery. Mastery, which is the extent to which people feel in control of the forces that affect their lives[17], has been found to be negatively associated with functional decline[18]. Self-efficacy refers to the confidence people have in being able to execute actions that are required to deal with particular situations[19;20] and appears to be related to the effectiveness of rehabilitation[21]. Furthermore, self-efficacy has been associated with stopping smoking[13], adherence to medication adherence[22] and to physical exercise[12], all important factors in the management of COPD[1].

Previous studies have shown that perceptions of personal control are important factors related to the outcomes of pulmonary rehabilitation[13;23-26], since these perceptions influence patients' motivation[19] to make the required efforts during rehabilitation. Since COPD patients referred for rehabilitation often experience multiple problems and have been found to experience a diminished sense of personal control, the treatment of these patients is rather difficult. Though a number of studies have reported the effects of rehabilitation on exercise tolerance and QoL[27], these effects often decrease in the long term[9;23;28;29]. The positive effects of rehabilitation are difficult to achieve and many patients experience relapse, even if they initially improved during rehabilitation[30;31]. As a result, patients with lower perceptions of personal control may fail to attain their goals during rehabilitation or may more easily relapse afterwards. Higher perceptions of personal control, however, may be related to better outcomes for pulmonary rehabilitation.

Consequently, in this study we first examined whether QoL and perceptions of mastery and self-efficacy improved in patients with COPD referred to a rehabilitation programme, compared to a reference group of COPD patients in an outpatient clinic who were not referred for rehabilitation. Given the often multiple and complex problems patients with COPD have to face, and a decreased level of motivation to change their behaviour, these patients were in fairly poor psychological shape, rendering it unlikely that changes in their perceptions of personal control during rehabilitation could be expected. Moreover, the assessed patients with COPD were quite seriously ill with respect to their lung function parameters (stage III of the GOLD classification (Global Initiative for Chronic Obstructive Lung Disease)[6], indicating serious COPD). Consequently, on the basis of previous research[30], only modest effects of pulmonary rehabilitation on the QoL of the patients were expected. Second, the possibility of a relationship between mastery and self-efficacy and QoL after rehabilitation was examined.

Methods

Participants

This study consisted of a consecutive sample of patients with COPD who participated in a pulmonary rehabilitation programme between January 2001 and April 2002. Patients who had been referred to a rehabilitation centre were compared with a reference group of outpatients in a general hospital who received usual care. Both the patients in rehabilitation and in the reference group were eligible for inclusion if they were 1) diagnosed as suffering from COPD, 2) aged between 40 and 80 years, 3) registered with a forced expiratory volume in 1 second (FEV_1) of less than 70% of the predicted value, 4) fluent in the Dutch language, 5) free from other pulmonary disease, 6) free from other serious non-pulmonary disease (such as heart disease or cancer), and 7) free from psychiatric problems in the previous year. In both centres, pulmonologists selected the patients who were suitable for participation in the study. Patients who met the criteria for inclusion received written information about the study and an informed consent form, requesting their permission to take part in the study. The Medical Ethics Committees of both centres approved the study.

Study design

We performed a longitudinal study consisting of two assessments collected by means of self-report questionnaires. Patients in pulmonary rehabilitation filled in questionnaires at the beginning (T1) and at the end (T2) of the rehabilitation programme. The length of the rehabilitation programme varied, with the average duration being 20 weeks. In the outpatient clinic, both T1 and T2 were marked by mailed questionnaires at a four-month interval. Incomplete questionnaires were returned, and patients were asked to complete the missing items.

Pulmonary rehabilitation

The basic part of the multidisciplinary programme consisted of pharmacological treatment, strength and endurance training and dietary interventions. In addition, psycho-education addressing the effects of chronic lung disease on the emotions, thoughts, and behaviour of COPD patients was included in the programme. Psychosocial problems related to the disorder were interpreted in the perspective of Kübler-Ross's theory of the stages of grief (shock, denial, depression, anger and adaptation)[32]. Further components of the rehabilitation programme addressed breathing strategies, relaxation training, and smoking cessation. Most patients participated in rehabilitation as outpatients, although patients were also able to participate as inpatients if they needed intensive nursing care or the travel time to the rehabilitation centre was too long.

Assessments

Clinical characteristics

Data concerning case history and clinical characteristics were collected from the patients' medical records. Lung function parameters (forced expiratory volume (FEV_1) in litres, FEV_1 %pred. and forced vital capacity (FVC) in litres) of the patients in rehabilitation were measured at the beginning of the rehabilitation programme. For the patients in the general hospital, the most recent assessment of these measures, within one to three months before T1, was used. Previous studies have shown that the annual rate of decline in FEV_1 for patients with COPD varies from 47 to 60 ml/year[33], although FEV_1 assessments within three to six months do not tend to fluctuate very much[34]. Furthermore, information on the number of pack-years ((number of years patients have smoked x number of cigarettes a day) / 20) and the lung disease duration was collected.

Symptoms of COPD
A short questionnaire measured dyspnoea during rest and exercise, sputum production and coughing during the last week[35]. The total scale consists of the average of the four items with a range from 0 to 6. Higher scores indicate more symptoms.

Quality of life
Three subscales of the Rand 36-item Health Survey[36;37] were selected for the assessment of QoL, covering the three major domains of QoL: *physical functioning* (10 items), *psychological functioning* (5 items) and *social functioning* (2 items). Physical functioning measures the extent to which health interferes with daily activities such as climbing stairs. Psychological functioning measures mood, including feelings of depression or tension. Social functioning assesses interference of health with normal social activities such as visiting friends or relatives. All subscales vary between 0 and 100; higher scores indicate better functioning.

Overall QoL was measured on Cantril's ladder[38], a scale ranging from 0 to 10, with higher scores indicating a higher overall QoL. Patients answered the question: 'Here is a picture of a ladder. Suppose the top of the ladder represents the best possible life for you and the bottom represents the worst possible life for you. Where on the ladder do you feel you personally stand at the present time?'

Perceptions of personal control
The Mastery scale of Pearlin & Schooler[39] measures the extent to which people feel they are in control of their own lives in general. Examples of items are: 'I have little control over the things that happen to me' or 'I can do just about anything I really set my mind to do'. This scale is composed of 5 positively formulated items and 2 negatively formulated items; the latter must be reversed. All items add up to a total score (range 7-35); higher scores indicate higher levels of mastery.

Self-efficacy was measured by the self-efficacy scale of Sullivan et al.[40], which consists of items assessing behaviours related to health. This scale consists of the *control symptoms* and *maintain function* subscales. The *control symptoms* subscale was measured by 6 items (range 0-24), such as 'How confident are you that you can control your breathlessness by taking your medications?'. The *maintain function* subscale consisted of 3 items (range 0-12), such as, 'How confident are you that you can get regular exercise?' Items for each scale add up to a total score; higher scores indicate higher levels of self-efficacy.

Socio-demographic variables
Age, gender, marital status and educational level were assessed. Educational level was assessed according to the International Standard Classification of Education[41;42], which has six categories that were recoded into four categories, ranging from lower educated to higher educated.

Statistics

First, t-tests and chi-square tests were performed to compare the demographic and clinical characteristics of patients in rehabilitation and patients in the reference group at T1. Second, paired-samples t-tests were carried out to study changes to QoL, symptoms and personal control over time within each group, and the differences between the groups at T1 and T2 was tested by means of analysis of (co)variance (corrected for age differences between the groups). Third, bi-variate correlation analyses were performed to study the associations of personal control at T1 with QoL at T2. In addition, multiple regression analyses of QoL at T2 on personal control at T1 were performed, and regression analyses of QoL at T2 on changes in personal control between T1 and T2, both adjusted for QoL at T1, age, and gender. The same QoL domains were measured at both T1 and at T2. The value of each QoL domain at T2 was used as a dependent variable in the regression analysis and was corrected for the initial value of the same QoL domain at T1.

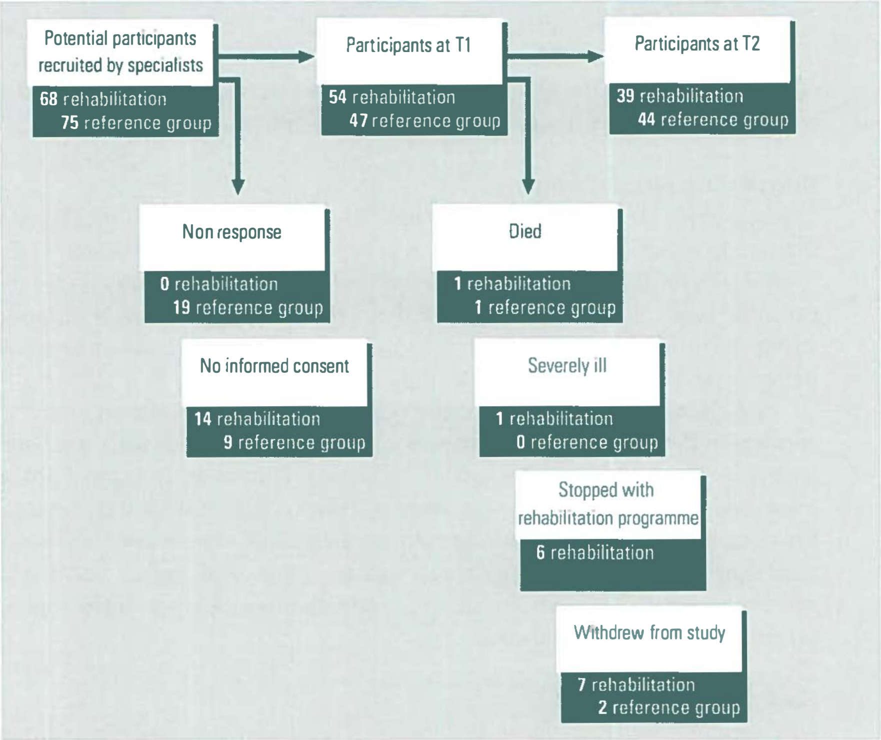

Figure 2.1 Flow diagram of participants

Results

Patient groups

Figure 2.1 shows the numbers of patients who were included in the study, including those who refused to participate and those who dropped out during the study. In rehabilitation, patients who refused to participate did not differ significantly from the respondents with respect to age and gender. In total, 54 patients were included (response rate was 79%) and 39 patients participated in both assessments. Patients who dropped out during the study scored significantly lower than the respondents in terms of vital capacity and physical and social functioning at T1; no significant differences were found with respect to demographic characteristics and perceptions of personal control.

Forty-seven patients participated in the study in the reference group (response rate was 63%) and 44 patients completed both assessments. Again, patients who refused to participate did not differ significantly from respondents in age or gender.

Socio-demographic variables

Table 2.1 lists the scores for the demographic variables and clinical characteristics of the patients with COPD in the study. Patients referred for rehabilitation were on average about 7 years younger ($p<0.001$) than the patients in the reference group. Other background parameters did not differ significantly between the groups.

Table 2.1 Demographic variables and clinical characteristics of COPD patients in rehabilitation and COPD patients in the reference group

	Rehabilitation N = 39		Reference group N = 44		Difference between groups
	Mean	SD	Mean	SD	p-value
Age (years)	60.5	9.0	68.0	8.2	.001[a]
Gender (% female)	41.0		34.1		n.s.
Educational level (%)					n.s.
Primary	28.3		45.4		
Lower vocational	35.9		27.3		
Secondary/intermediate vocational	17.9		18.2		
Higher vocational/university	17.9		9.1		
Marital status (% with partner)	84.6		88.4		n.s.
FEV_1 (litres)	1.2	0.6	1.4	0.7	n.s.
FEV_1 (%pred)	40.7	21.1	46.9	16.1	n.s.
FVC (litres)	3.2	0.9	3.3	0.9	n.s.
Pack-years (years)	41.5	29.4	33.7	21.2	n.s.
Illness duration (years)	8.6	8.4	11.7	12.0	n.s.

n.s. = not significant

[a]) t-value = 4.0

Table 2.2 QoL and perceptions of personal control (mastery and self-efficacy) for patients with COPD in rehabilitation and COPD patients in the reference group

	Rehabilitation					Reference group				
	T1		T2		T2-T1	T1		T2		T2-T1
	Mean[a]	SD	Mean[a]	SD	p-value[b]	Mean[a]	SD	Mean[a]	SD	p-value[b]
Quality of Life										
Physical functioning	30.0[c]	19.7	35.0[d]	21.4	n.s.	41.1	28.9	41.1	29.9	n.s.
Social functioning	51.3	25.3	59.0	25.5	n.s.	65.1	29.0	64.8	26.7	n.s.
Psychological functioning	66.3	18.8	68.2	20.9	n.s.	72.2	19.6	71.2	18.5	n.s.
COPD specific symptoms	3.0	1.0	2.9	1.1	n.s.	2.7	1.1	2.9	1.2	n.s.
Overall QoL	5.3[e]	1.4	5.9	1.7	.03[f]	6.1	1.5	6.3	1.5	n.s.
Personal control										
Mastery	22.6	5.1	21.2	4.7	n.s.	23.1	4.2	23.1	4.9	n.s.
Self-efficacy *control symptoms*	17.8	3.2	19.7	2.9	.002[g]	19.2	3.3	19.9	2.6	n.s.
Self-efficacy *maintain function*	7.2	2.4	8.0	2.6	n.s.	7.3	1.9	7.6	2.5	n.s.

n.s. = not significant

[a]) unadjusted means (uncorrected for age differences between groups); [b]) adjusted p-values

Analysis of variance between groups: [c]) vs. T1 reference group F-value = 5.6, p = .02;

[d]) vs. T2 reference group F-value = 4.0, p = .05; [e]) vs. T1 reference group F-value = 3.9, p = .05

Paired t-tests within groups (T2-T1): [f]) t-value = -2.2; [g]) t-value = -3.3

Differences between the patient groups in QoL, symptoms, and personal control

Table 2.2 reveals that, at T1, patients in rehabilitation scored significantly lower in self-reported physical functioning compared with the patients in the reference group. Furthermore, patients in rehabilitation scored significantly lower in overall QoL than the reference group. At T2, the patients in rehabilitation still functioned at a significantly lower level with respect to physical functioning than the reference group. The groups did not differ significantly in personal control at T1 and T2.

Changes in QoL, symptoms and personal control within the groups between T1 and T2

Table 2.2 also shows the changes within the groups between T1 and T2. Patients in rehabilitation showed significant improvements between T1 and T2 in overall QoL and in the *control symptoms* self-efficacy subscale, whereas the reference group did not change significantly in these variables. QoL domains, symptoms of COPD, and mastery did not change significantly in either group.

Although on average QoL domains of patients in rehabilitation did not change significantly, further analyses of individual patients showed that a significant number of patients improved with respect to physical functioning compared to the reference group. Of the patients in rehabilitation, 36% showed significant improvements in physical functioning in contrast to 9% in the reference group ($\chi^2 = 9.01$, $p < 0.05$). The number of patients that improved in social and psychological functioning did not differ significantly between the groups.

Relationships between personal control and QoL domains

Table 2.3 contains the Pearson's correlation coefficients for the relationships between QoL domains, mastery, and self-efficacy at T1 with QoL domains at T2 for the rehabilitation group. In addition, correlation coefficients are shown for changes in mastery and self-efficacy between T1 and T2 with QoL at T2.

We found significant relationships between each QoL domain at T1 and the same QoL domain at T2. Perceptions of personal control at T1 were not significantly related to QoL at T2. Changes in self-efficacy *maintain function* were significantly related to social and psychological functioning at T2 ($r = 0.50$, $p < 0.01$ and $r = 0.35$, $p < 0.05$).

Correlation analyses at T1 and T2 revealed the following results (additional information, which is not displayed in the table): self-efficacy *maintain function* at T1 was significantly related to social functioning ($r = 0.40$, $p < 0.05$) and marginally significantly related to psychological functioning ($r = 0.31$, $p = 0.058$) and physical functioning ($r = 0.31$, $p = 0.059$). Self-efficacy *control symptoms* was only significantly related to psychological functioning ($r = 0.41$, $p < 0.05$). Mastery was related to psychological functioning ($r = 0.40$, $p < 0.05$) and overall QoL ($r = 0.39$, $p < 0.05$), and marginally significantly related to physical functioning ($r = 0.31$, $p = 0.057$). At T2, self-efficacy *maintain function* was significantly related to all QoL domains and overall QoL ($r = 0.44$ to $r = 0.65$, $p < 0.01$), whereas self-efficacy *control symptoms* was not significantly related to any of the domains and overall QoL. Mastery was significantly related to overall QoL ($r = 0.34$, $p < 0.05$) and marginally significantly related to physical functioning ($r = 0.31$, $p = 0.067$).

Table 2.3 Pearson's correlation coefficients of QoL (Rand-36) and perceptions of personal control (mastery and self-efficacy) for patients with COPD in rehabilitation (N = 39)

	T2 Physical functioning	T2 Social functioning	T2 Psychological functioning	T2 Overall QoL
T1 QoL				
Physical functioning	.42*	-.01	-.24	-.10
Social functioning	.40*	.51**	.45**	.33
Psychological functioning	.40*	.52***	.71***	.46**
T1 Overall QoL	.27	.27	.38*	.30
T1 Personal control				
Mastery	.16	.12	.19	.06
Self-efficacy *control symptoms*	-.06	.08	.29	.06
Self-efficacay *maintain function*	.25	.09	.14	.29
Δ Personal control				
Mastery	.12	.15	.07	.24
Self-efficacy *control symptoms*	-.00	.16	-.04	.15
Self-efficacay *maintain function*	.18	.50**	.35*	.19

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

Independent associations between personal control and QoL domains

Table 2.4 shows the contribution of personal control to QoL domains after rehabilitation. The first regression analysis yielded no significant associations between either mastery or self-efficacy subscale *control symptoms* at T1 and any of the QoL measures at T2. Self-efficacy subscale *maintain function* was only marginally significantly related to overall QoL at T2 ($\beta = 0.32$, $p = 0.073$).

The second regression analysis showed that changes during rehabilitation in self-efficacy *maintain function* contributed significantly to the explanation of changes in social functioning ($\beta = 0.48$, $p < 0.001$) and psychological functioning ($\beta = 0.39$, $p < 0.01$). Changes in self-efficacy subscale *control symptoms* were not significantly related to any of the QoL domains nor to overall QoL. Changes in mastery were only marginally significantly related to the explanation of changes in physical functioning ($\beta = 0.27$, $p = 0.085$) and overall QoL ($\beta = 0.33$, $p = 0.054$).

Discussion

The results of this study showed that the COPD patients improved with respect to overall QoL and self-efficacy during the rehabilitation programme. Interestingly, the reference group did not change significantly for any of the variables in the study. In addition, changes during rehabilitation in self-efficacy contributed to the explana-

Table 2.4 Regression of QoL domains at T2 on perceptions of personal control at T1 for COPD patients in rehabilitation (N = 39)

Predictors	Physical functioning T2			Social functioning T2			Psychological functioning T2			Overall QoL T2		
	B	β	Δ R^2	B	β	Δ R^2	B	β	Δ R^2	B	β	Δ R^2
Analysis 1[a]												
QoL domain T1	.33	.31		.50	.49**		.96	.86***		.29	.23	
Mastery T1	-.39	-.09		-.42	-.08		-.55	-.13		-.04	-.13	
Self-efficacy *control symptoms* T1	.27	.04		.80	.10		-.04	-.01		.02	.03	
Self-efficacy *maintain function* T1	1.83	.22		.47	.05		-1.13	-.13		.22	.32[b]	
			.17			.27			.54			.17
Analysis 2[c]												
QoL domain T1	.46	.45**		.40	.42**		.84	.75***		.49	.38*	
Δ Mastery	1.01	.27[d]		.98	.21		.73	.18		.11	.33[e]	
Δ Self-efficacy *control symptoms*	-.15	-.03		1.00	.14		.39	.06		.13	.25	
Δ Self-efficacy *maintain function*	1.88	.26		4.12	.48***		2.92	.39**		.16	.27	
			.24			.49			.66			.27

[a]) regression analyses of QoL domains at T2 on control variables at T1; [b]) β = .32, p = .073

[c]) regression analyses of QoL domains at T2 on changes in personal control (T2 - T1); [d]) p = .085; [e]) p = .054

[a,c]) regression analyses were corrected for age, gender, and the level of the specific QoL domain at T1

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

tion of the social and psychological QoL domains after rehabilitation, which is consistent with earlier findings reported by Lox[12] and McCathie[26].

Quality of life

Patients in rehabilitation scored significantly worse with respect to physical functioning than the patients in the reference group at both assessments, although on average both groups scored much lower than healthy people of the same age (healthy people 64.8 (SD 26.4)[37]; rehabilitation group 30.0 (SD 19.7), reference group 41.1 (SD 28.9)). Considering their FEV$_1$, patients in both groups in this study are in stage III according to the GOLD guidelines[6], indicating that both groups of patients with COPD are extensively impaired and in need of careful management.

In this study, no significant improvement in physical functioning was found at group level during rehabilitation. Previous research did report significant improvements in physical functioning measured by the SF-36[43;44], thereby demonstrating the sensitivity of this measure to assess changes in QoL during rehabilitation. The COPD patients in this study were in advanced stages of their illnesses and therefore, the possibilities for improvement with respect to physical aspects of QoL were probably limited[30]. Previous research has shown that during the course of their illness, COPD patients gradually decline with respect to pulmonary function and with respect to physical and other domains of QoL[34;45]. This process of deterioration can only be retarded, with medication for instance, but not stopped[33]. This may also explain the fact that significant improvements in self-reported physical functioning during rehabilitation were not found at group level. Although the physical condition of the COPD patients in rehabilitation is rather poor, psychosocial adjustment to the illness is still possible, which is supported by our result that COPD patients improved during rehabilitation with respect to their overall QoL.

Personal control

The finding that COPD patients in rehabilitation reported significant changes in self-efficacy is consistent with earlier findings[9;12;46]. However, the COPD patients in this study were seriously ill, illustrated by the result that no improvements with respect to QoL domains were found. Moreover, in order to realise positive rehabilitation effects, the patients are required to change certain unhealthy behaviours, which is rather difficult for patients often suffering from multiple psychosocial problems and demotivation[7;11]. Consequently, the results of this study, showing a significant improvement in self-efficacy during rehabilitation, are rather remarkable. Only a few other studies have assessed perceptions of personal control in patients with COPD[14;47-50] and, therefore, this study adds to the existing literature on changes in self-efficacy during pulmonary rehabilitation.

After rehabilitation, patients reported more confidence in their ability to exert control over their symptoms. Self-efficacy theory assumes that perceptions of personal efficacy are based on previous experiences of successful performance or learning experiences[19;51], hence exercise training may lead to higher perceptions of self-efficacy[52]. Since pulmonary rehabilitation is tailored to the abilities of individual patients, the individual goals of the programme are readily achievable, which probably results in an improvement in perceptions of self-efficacy. The result that no improvements in mastery were found during rehabilitation shows that the changes in personal control during rehabilitation are specific rather than general.

Contribution of self-efficacy to QoL domains

Improvements in the self-efficacy subscale *maintain function* were related to improved social and psychological functioning after rehabilitation, while changes in self-efficacy *control symptoms* were not related to QoL after rehabilitation. Improvements in self-efficacy *control symptoms* probably do not lead to a better QoL as actual control over the symptoms patients experience is limited. Self-efficacy *maintain function* concerns the confidence patients have in being able to engage in physical activities. As a result of low perceptions of self-efficacy, COPD patients may refrain from the activities of daily life[53]. Increased perceptions of self-efficacy *maintain function* may encourage patients to engage in social activities more often, which in turn may enhance their feelings of well-being.

Study limitations

This study has a few limitations. First, since we did not randomly assign the patients to the different treatments, we cannot firmly conclude whether the changes in self-efficacy during rehabilitation can be attributed to the rehabilitation programme. However, both patient groups were comparable with respect to most background variables and clinical characteristics. Both patient groups were in advanced stages of their illnesses and reported a lower QoL and mastery compared to healthy people (mastery scores for healthy people 24.7 (SD 5.3)[18]; rehabilitation 22.6 (SD 5.1), reference group 23.1 (SD 4.2)). The reference group, in which no intervention was administered, showed no significant changes in QoL or personal control. Therefore, at least part of the improvements in self-efficacy and overall QoL in the rehabilitation group probably result from the rehabilitation programme.

Second, both groups of patients are fairly heterogeneous with respect to clinical characteristics and QoL domains. Therefore, caution has to be exercised in drawing conclusions regarding the differences between the groups, since there are considerable differences within the groups.

Third, unfortunately a reasonably large number of patients in rehabilitation dropped out during the study, mainly due to their leaving the programme. Although the patients who dropped out scored significantly lower than the participants on a few variables in the study, no significant differences have been found with respect to perceptions of personal control and, therefore, the amount of drop-out probably did not affect our results.

Practice implications

A finding of interest for health care professionals is that the patients in rehabilitation and the reference group did not differ with respect to pulmonary function, while the patients in rehabilitation functioned significantly worse with respect to self-reported physical functioning. This suggests that patients are more often referred for rehabilitation on the basis of their limitations in daily physical activities than on the basis of pulmonary function. Furthermore, these results suggest a discrepancy between pulmonary function and perceptions of limitations in physical functioning, which is in line with earlier studies that have showed discrepancies between self-reported and more objectively assessed physical functioning[54;55].

An important result of this study is that the patients improved during rehabilitation with respect to self-efficacy. In the treatment of patients with COPD, aside from improving physical functioning, enhancing health promoting behaviours is important as these behaviours promote better disease management. Higher levels of self-efficacy are associated with healthy behaviours, such as smoking cessation[13], more physical exercise, and higher training achievements[56]. Therefore, interventions for patients with COPD should not only focus on improving physical functioning but also on enhancing perceptions of self-efficacy. In patients with COPD in particular, strengthening perceptions of personal control is very important, since these perceptions of control in turn affect the motivation to engage in healthy behaviours[19]. To date, strengthening the control beliefs of COPD patients is only an implicit goal of rehabilitation, although rehabilitation programmes are appropriate interventions to enhance both self-efficacy and physical functioning[12]. Therefore, enhancing perceptions of self-efficacy is suggested as being an important aim in the treatment of patients with COPD.

Conclusions

COPD patients improved with respect to overall QoL and personal control during a rehabilitation programme. Furthermore, this study revealed a relationship between changes during rehabilitation in perceptions of self-efficacy with QoL, suggesting that perceptions of personal control, and self-efficacy in particular, play an important part in the adjustment to COPD. These results show that even in seriously impaired COPD patients in advanced stages of illness, positive changes in self-efficacy and overall well-being can be established during rehabilitation.

The results of pulmonary rehabilitation, however, are often not maintained for a long period[9;30]. Previous studies have argued that perceptions of personal control influence patients' motivation[19] to exert effort for certain activities, and have been associated with lifestyle changes, such as physical exercise and smoking cessation[12;13]. Consequently, the role of self-efficacy may be very important in maintaining the effects of rehabilitation. It would thus be of interest to study whether the changes in self-efficacy are maintained after the end of the rehabilitation programme and whether this is associated with enduring changes in lifestyle factors.

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Reference List

1 Pauwels RA, Buist AS, Ma P, Jenkins CR, Hurd SS. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. National Heart, Lung, and Blood Institute and World Health Organization Global Initiative for Chronic Obstructive Lung Disease (GOLD): executive summary. Respir Care 2001; 46: 798-825.

2 American Thoracic Society. Standards for the diagnosis and care of patients with chronic obstructive pulmonary disease. Am J Respir Crit Care Med 1995; 152: S77-121.

3 Rennard SI. COPD: overview of definitions, epidemiology, and factors influencing its development. Chest 1998; 113: 235S-241S.

4 Stavem K, Lossius MI, Kvien TK, Guldvog B. The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. Qual Life Res 2000; 9: 865-871.

5 Yohannes AM, Baldwin RC, Connolly MJ. Depression and anxiety in elderly outpatients with chronic obstructive pulmonary disease: prevalence, and validation of the BASDEC screening questionnaire. Int J Geriatr Psychiatry 2000; 15: 1090-1096.

6 Global Initiative for Chronic Obstructive Lung Disease. Global strategy for the diagnosis, management, and prevention of Chronic Obstructive Pulmonary Disease. NHLBI/WHO workshop report. Update of the management sections. National Heart, Lung and Blood Institute. 2003 Jul 1 [cited 2004 Mar 4] Available from: http://www.goldcopd.com.

7 Lareau SC, ZuWallack R, Carlin B, Celli B, Fahy B, Gosselink R, Jones P, Larson JL, Meek P, Rochester C, Sassi-Dambron D, Stubbing D. Pulmonary rehabilitation-1999. American Thoracic Society. Am J Respir Crit Care Med 1999; 159: 1666-1682.

8 Berry MJ, Rejeski WJ, Adair NE, Zaccaro D. Exercise rehabilitation and chronic obstructive pulmonary disease stage. Am J Respir Crit Care Med 1999; 160: 1248-1253.

9 Ries AL, Kaplan RM, Limberg TM, Prewitt LM. Effects of pulmonary rehabilitation on physiologic and psychosocial outcomes in patients with chronic obstructive pulmonary disease. Ann Intern Med 1995; 122: 823-832.

10 Anthonisen NR, Connett JE, Murray RP. Smoking and lung function of Lung Health Study participants after 11 years. Am J Respir Crit Care Med 2002; 166: 675-679.

11 Büchi S, Wolf C, Schwarz F, Villiger B, Buddeberg C. Sind stationäre Rehabilitationsbehandlungen bei Patienten mit chronisch obstruktiver Lungenkrankheit (COLK) sinnvoll? Ergebnisse einer prospektiven 1-Jahres-Verlaufsstudie. Psychother Psychosom Med Psychol 1996; 46: 423-429.

12 Lox CL, Freehill AJ. Impact of pulmonary rehabilitation on self-efficacy, quality of life, and exercise tolerance. Rehab Psychol 1999; 44: 208-221.

13 Meland E, Maeland JG, Laerum E. The importance of self-efficacy in cardiovascular risk factor change. Scand J Public Health 1999; 27: 11-17.

14 Toshima MT, Kaplan RM, Ries AL. Self-efficacy expectancies in chronic obstructive pulmonary disease rehabilitation. In: Schwarzer R, ed. Self-efficacy: thought control of action. Washington, DC, US: Hemisphere Publishing Corp., 1992: 325-354.

15 Skinner EA. A guide to constructs of control. J Pers Soc Psychol 1996; 71: 549-570.

16 Gurin P, Gurin G, Morrison BM. Personal and ideological aspects of internal and external control. Soc Psychol 1978; 41: 275-296.

17 Pearlin LI, Lieberman MA, Menaghan EG, Mullan JT. The stress process. J Health Soc Behav 1981; 22: 337-356.
18 Kempen GIJM, Sanderman R, Miedema I, Meyboom-de Jong B, Ormel J. Functional decline after congestive heart failure and acute myocardial infarction and the impact of psychological attributes. A prospective study. Qual Life Res 2000; 9: 439-450.
19 Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 1977; 84: 191-215.
20 Carver C, Harris S, Lehman J, Durel L, Antoni M, Spencer S, Pozo-Kaderman C. How important is the perception of personal control? Studies of early stage breast cancer patients. Pers Soc Psychol Bull 2000; 26: 139-149.
21 Berkhuysen MA, Nieuwland W, Buunk BP, Sanderman R, Rispens P. Change in self-efficacy during cardiac rehabilitation and the role of perceived overprotectiveness. Patient Educ Couns 1999; 38: 21-32.
22 Gifford AL, Bormann JE, Shively MJ, Wright BC, Richman DD, Bozzette SA. Predictors of self-reported adherence and plasma HIV concentrations in patients on multidrug antiretroviral regimens. J Acquir Immune Defic Syndr 2000; 23: 386-395.
23 Büchi S, Villiger B, Sensky T, Schwarz F, Wolf C, Buddeberg C. Psychosocial predictors of long-term success of in-patient pulmonary rehabilitation of patients with COPD. Eur Respir J 1997; 10: 1272-1277.
24 Lorig KR, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter P, Gonzalez VM, Laurent DD, Holman HR. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care 1999; 37: 5-14.
25 Ketelaars CA, Schlosser MA, Mostert R, Huyer-Abu-Saad H, Halfens RJ, Wouters EF. Determinants of health-related quality of life in patients with chronic obstructive pulmonary disease. Thorax 1996; 51: 39-43.
26 McCathie HCF, Spence SH, Tate RL. Adjustment to chronic obstructive pulmonary disease: the importance of psychological factors. Eur Respir J 2002; 19: 47-53.
27 Goldstein RS, Gort EH, Stubbing D, Avendano MA, Guyatt GH. Randomised controlled trial of respiratory rehabilitation. Lancet 1994; 344: 1394-1397.
28 Griffiths TL, Burr ML, Campbell IA, Lewis-Jenkins V, Mullins J, Shiels K, Turner-Lawlor PJ, Payne N, Newcombe RG, Ionescu AA, Thomas J, Tunbridge J, Lonescu AA. Results at 1 year of outpatient multidisciplinary pulmonary rehabilitation: a randomised controlled trial. Lancet 2000; 355: 362-368.
29 Strijbos JH, Postma DS, van Altena R, Gimeno F, Koeter GH. A comparison between an outpatient hospital-based pulmonary rehabilitation program and a home-care pulmonary rehabilitation program in patients with COPD. A follow-up of 18 months. Chest 1996; 109: 366-372.
30 Ketelaars CA, Abu-Saad HH, Schlosser MA, Mostert R, Wouters EF. Long-term outcome of pulmonary rehabilitation in patients with COPD. Chest 1997; 363-369.
31 Wempe JB, Wijkstra PJ. The influence of rehabilitation on behaviour modification in COPD. Patient Educ Couns 2004; 52: 237-241.
32 Kübler-Ross E. On death and dying. New York: Macmillan, 1969.

33 Sutherland ER, Allmers H, Ayas NT, Venn AJ, Martin RJ. Inhaled corticosteroids reduce the progression of airflow limitation in chronic obstructive pulmonary disease: a meta-analysis. Thorax 2003; 58: 937-941.

34 Burge PS, Calverley PM, Jones PW, Spencer S, Anderson JA, Maslen TK. Randomised, double blind, placebo controlled study of fluticasone propionate in patients with moderate to severe chronic obstructive pulmonary disease: the ISOLDE trial. BMJ 2000; 320: 1297-1303.

35 Van der Molen T, Willemse BMW, Schokker S, Ten Hacken NHT, Postma DS, Juniper EF. Development, validity and responsiveness of the Clinical COPD Questionnaire. Health Qual Life Outcomes [serial online] 2003 Apr 28 [cited 2003 Aug 5];1;[10 screens]. Available from: URL: http://www.hqlo.com/content/1/1/13.

36 Ware JE, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36) : I. Conceptual framework and item selection. Med Care 1992; 30: 473-483.

37 Van der Zee K, Sanderman R, Heyink JW, De Haes HCJM. Psychometric qualities of the RAND 36-item Health Survey 1.0: a multidimensional measure of general health status. Int J Behav Med 1996; 3: 104-122.

38 Cantril H. Discovering people's aspirations: the method used. In: Cantril H, ed. The pattern of human concerns. New Brunswick, NJ: Rutgers University Press, 1965: 21-29.

39 Pearlin LI, Schooler C. The structure of coping. J Health Soc Behav 1978; 19: 2-21.

40 Sullivan MD, LaCroix AZ, Russo J, Katon WJ. Self-efficacy and self-reported functional status in coronary heart disease: a six-month prospective study. Psychosom Med 1998; 60: 473-478.

41 United Nations Educational Scientific and Cultural Organization. International Standard Classification of Education (ISCED). Paris, France: UNESCO, 1976.

42 Ranchor AV, Bouma J, Sanderman R. Vulnerability and social class: differential patterns of personality and social support over the social class. Pers Indiv Dif 1996; 20: 229-237.

43 Boueri FMV, Bucher-Bartelson BL, Glenn KA, Make BJ. Quality of life measured with a generic instrument (Short Form-36) improves following pulmonary rehabilitation in patients with COPD. Chest 2001; 119: 77-84.

44 Ward JA, Akers G, Ward DG, Pinnuck M, Williams S, Trott J, Halpin DMG. Feasibility and effectiveness of a pulmonary rehabilitation programme in a community hospital setting. Br J Gen Pract 2002; 52: 539-542.

45 Spencer S, Calverley PM, Sherwood-Burge P, Jones PW. Health status deterioration in patients with chronic obstructive pulmonary disease. Am J Respir Crit Care Med 2001; 163: 122-128.

46 Zimmerman BW, Brown ST, Bowman JM. A self-management program for chronic obstructive pulmonary disease: relationship to dyspnea and self-efficacy. Rehabil Nurs 1996; 21: 253-257.

47 Van der Palen J, Klein J, Seydel E. Are high generalized and asthma-specific self-efficacy predictive of adequate self-management behaviour among adult asthma patients? Patient Educ Couns 1997; 32: S35-S41.

48 Kohler CL, Fish L, Greene PG. The relationship of perceived self-efficacy to quality of life in chronic obstructive pulmonary disease. Health Psychol 2002; 21: 610-614.

49 Scherer YK, Schmieder LE. The effect of a pulmonary rehabilitation program on self-efficacy, perception of dyspnea, and physical endurance. Heart Lung 1997; 26: 15-22.

50 Kaplan RM, Ries AL, Prewitt LM, Eakin E. Self-efficacy expectations predict survival for patients with chronic obstructive pulmonary disease. Health Psychol 1994; 13: 366-368.
51 Holman HR, Lorig K. Perceived self-efficacy in self-management of chronic disease. In: Schwarzer R, ed. Self-efficacy: thought control of action. Washington, DC, US: Hemisphere Publishing Corp., 1992: 305-323.
52 Stewart KJ, Kelemen MH, Ewart CK. Relationships between self-efficacy and mood before and after exercise training. J Cardiopulm Rehabil 1994; 14: 35-42.
53 Wigal JK, Creer TL, Kotses H. The COPD Self-Efficacy Scale. Chest 1991; 99: 1193-1196.
54 Singh SJ, Sodergren SC, Hyland ME, Williams J, Morgan MDL. A comparison of three disease-specific and two generic health-status measures to evaluate the outcome of pulmonary rehabilitation in COPD. Respir Med 2001; 95: 71-77.
55 Wijnhoven HA, Kriegsman DM, Hesselink AE, Penninx BW, de Haan M. Determinants of different dimensions of disease severity in asthma and COPD: pulmonary function and health-related quality of life. Chest 2001; 119: 1034-1042.
56 Ewart CK. Role of physical self-efficacy in recovery from heart attack. In: Schwarzer R, ed. Self-efficacy: thought control of action. Washington, DC, US: Hemisphere Publishing Corp., 1992: 287-304.

3

The relationship between self-efficacy and self-reported physical functioning in Chronic Obstructive Pulmonary Disease and Chronic Heart Failure

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Abstract

Objective

This study investigated whether self-reported physical functioning of patients with Chronic Obstructive Pulmonary Disease (COPD) and Chronic systolic Heart Failure (CHF) was primarily explained by illness-specific differences related to diagnosis, or whether more generic factors also contributed to their physical functioning.

Methods

Consecutive patients with COPD (N=56; aged 67.8±8.5) and CHF (N=65; aged 60.0±10.2) from the outpatient clinics of a university hospital and a general hospital completed a self-report questionnaire, including the Rand-36 Health Survey, Cantril's ladder, the Mastery scale, the Perceived Health Competence Scale, and the Self-efficacy scale.

Results

COPD patients scored significantly worse in self-reported physical and psychological functioning and perceived health competence than patients with CHF. Regression analysis revealed that both the diagnosis and the illness severity contributed to self-reported physical functioning, although self-efficacy explained the main part of physical functioning. Therefore, not only improving physical functioning but also enhancing perceptions of self-efficacy should be important aims in the treatment of patients with COPD and CHF.

Submitted

Introduction

Chronic Obstructive Pulmonary Disease (COPD) and Chronic systolic Heart Failure (CHF) are both seriously debilitating conditions that have a profound impact on both the functional status[1] and the quality of life (QoL) of the patients[2;3]. These illnesses are readily comparable with respect to clinical characteristics: both COPD and CHF are progressive illnesses, characterised by breathlessness and diminished exercise capacity[4]. Furthermore, both illnesses are to a certain extent related to unhealthy habits, such as smoking. This study compared patients with COPD and CHF with respect to QoL, in particular physical aspects of QoL, and studied which clinical and psychological factors were related to the QoL of the patients.

In general, QoL is divided into physical, social, and psychological domains.[5] Research studying patients with chronic lung and heart conditions reported that, compared with healthy people, both patient groups showed a lower physical, social, and psychological functioning[6;7]. Although patients with COPD and CHF probably experience comparable functional limitations, there may be differences between the diseases in the extent to which QoL domains are affected[8], since the underlying causes of the functional limitations are quite different for COPD and CHF. However, the factors that contribute to physical functioning in COPD and CHF may be comparable. For instance, irrespective of the kind of diagnosis, the severity of the specific illness – the number of symptoms for instance – may be an important determinant of physical functioning.

One psychological factor which may be related to the physical domain of QoL is personal control. Personal control refers to individuals' belief about their capacity to exert control over their own lives[9]. Previous research has revealed that during the development of a chronic illness, patients' perceptions of personal control are affected[10]. Furthermore, more personal control could be related to a better QoL and well-being[11], and improved physical functioning[12]. Consequently, personal control seems to be an intermediate factor in the relationship between a chronic illness and the patients' QoL.

Several forms of personal control have been described, ranging from the more general to the more specific. Mastery is the extent to which people feel they are in control over their own lives in general[13] and has been found to be negatively associated with functional decline[14]. Another form of personal control, which refers to control over health, is perceived health competence[15]. Previous research has shown a relationship between a greater perceived health competence and added preventive health behaviour, such as exercise, abstinence from smoking, and weight maintenance[16]. A third form of personal control is self-efficacy, which concerns control over specific behaviours necessary in handling an illness. Self-efficacy has also been associated with health promoting behaviours, such as stopping smoking[17], adherence to medication[18], and physical exercise[19]. Thus, since associations were found between several forms of personal control and functional status and health-related behaviours, personal control is probably also related to the QoL of patients.

The main focus of this study was to investigate whether self-reported physical functioning of patients with COPD and CHF was primarily explained by illness-specific differences related to diagnosis, and whether more generic factors also contribute to physical functioning. We hypothesised that diagnosis type and illness severity contribute to physical functioning both directly and indirectly through personal control (see Figure 3.1). As a secondary purpose of this study, the patients with COPD and CHF were compared with respect to QoL domains and perceptions of personal control.

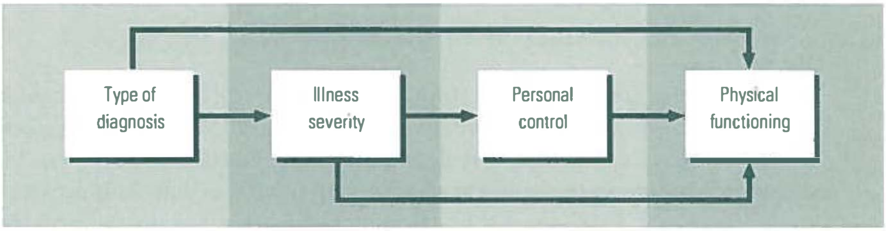

Figure 3.1 Model regression analysis

Method

Patients and study design

Consecutive patients with COPD or CHF were recruited from April 2001 to June 2002 in the outpatient clinics of a university hospital and a general hospital. Eligible patients received written information about the study and an informed consent form. Patients were included if they were (1) diagnosed with COPD or CHF, (2) aged between 40 and 80 years, (3) registered with a forced expiratory volume in 1 second (FEV_1) of less than 70% of the predicted value for COPD or a left ventricular ejection fraction (LVEF) of less than 45% for CHF, (4) free from other pulmonary or cardiovascular disease, (5) free from other serious disease (such as cancer), (6) free from psychiatric problems in the last year, and (7) fluent in the Dutch language. The study had a cross-sectional design and data were collected by means of self-report mailed questionnaires. The Medical Ethics Committees of both centres approved the study.

Assessments

Clinical characteristics

Data on lung function parameters (FEV_1 in litres, FEV_1 %pred and FVC in litres) were collected in the group of patients with COPD from the patients' medical records. Information on left ventricular ejection fraction (LVEF) and New York Heart Association (NYHA) functional class was collected for the patients with CHF. Furthermore, the number of pack-years ((number of years patients smoked x number of cigarettes per day) / 20) and illness duration were assessed.

Illness severity

In order to be able to compare patients with COPD and CHF in this study with respect to the severity of their illnesses, we constructed a generic index that distinguished between severely and moderately severely affected patients, based on the FEV$_1$ %pred for COPD patients and the LVEF for CHF. The patients with COPD were classified according to the GOLD criteria[20] into a severe group (FEV$_1$ %pred < 50%) and a moderately severe group (50% = FEV$_1$ %pred < 70%). Patients with CHF were divided into a severe group (LVEF < 30%) and a moderately severe group (30% = LVEF < 45%), in line with previous studies[21;22].

Quality of life

Three subscales from the Rand 36-item Health Survey[23;24] were selected for the assessment of QoL, covering the three major domains of QoL: *physical functioning* (10 items), *psychological functioning* (5 items) and *social functioning* (2 items). Physical functioning measures the extent to which health interferes with daily activities such as climbing stairs. Psychological functioning measures mood, including feelings of depression or tension. Social functioning assesses interference of health with normal social activities such as visiting friends or relatives. All subscales vary from 0 to 100; higher scores indicate better functioning.

Overall QoL was measured on Cantril's ladder[25], a scale ranging from 0 to 10, with higher scores indicating a higher overall QoL. Patients answered the question: 'Here is a picture of a ladder. Suppose the top of the ladder represents the best possible life for you and the bottom represents the worst possible life for you. Where on the ladder do you feel you personally stand at the present time?'

Perceptions of personal control

The Pearlin & Schooler *Mastery* scale[26] measures the extent to which people feel they are in control over their own lives. Examples of items are 'I have little control over the things that happen to me' or 'I can do just about anything I really set my mind to do'. This scale consists of 5 positively formulated items and 2 negatively formulated items; the latter must be reversed. All items add up to a total score (range 7-35); higher scores indicate higher levels of personal control perceptions.

The *Perceived Health Competence Scale*[15] measures the degree to which individuals feel capable of effectively managing their health outcomes. This scale consists of 4 positively formulated items and 4 negatively formulated items. All items add up to a total score (range 8-40); higher scores indicate higher levels of competence. Examples of items are 'I handle myself well with respect to my health', and 'No matter how hard I try, my health just doesn't turn out the way I would like'.

Self-efficacy was measured on the self-efficacy scale of Sullivan et al.[27] which consists of items concerning behaviours related to health. This scale consists of the *control symptoms* and *maintain function* subscales. The *control symptoms* subscale was measured with 6 items (range 0-24), such as 'How confident are you that you can control your breathlessness by taking your medications?'. The *maintain function* subscale consisted of 3 items (range 0-12), for example 'How confident are you that you can get regular exercise?' Items for each scale are added up to a total score; higher scores indicate higher levels of self-efficacy.

Socio-demographic variables

Age, gender, marital status and educational level were assessed. Educational level was assessed according to the International Standard Classification of Education[28;29], which has four categories from lower to higher educated.

Data analysis

First, t-tests and chi-square tests were performed to compare both patient groups with respect to demographic and clinical characteristics. Second, the differences between the groups with respect to QoL and personal control were tested by means of analysis of variance to control for age differences between the groups. Third, bivariate correlation analyses were performed to study the associations of illness severity, QoL, and personal control. In addition, a multiple regression analysis of physical functioning on diagnosis type, illness severity, and personal control was performed. Since the study focussed on the question of whether differences in physical functioning could be explained mainly by illness-specific or generic factors, the groups were combined in the regression analysis. The diagnosis and age variables were entered in the first step of the regression analysis. The illness severity variable was entered in the next step, and in the final step, personal control variables were entered into the analysis.

Results

Patient groups

Eighty-six patients with COPD were asked to participate in the study, 19 of whom did not respond and 11 refused. Patients who did not participate did not differ significantly from the respondents with respect to age and gender. Fifty-six patients were included in total (response rate 65%). In the group of patients with CHF, 110 patients were invited for participation, 45 of whom refused. Sixty-five patients participated in the study (response rate 59%). Patients refusing to participate did not differ significantly from respondents with respect to gender. A significant difference was found in the CHF group with respect to age: patients refusing to participate were on average 9 years older than the participants.

Socio-demographic variables

Table 3.1 shows that the patients with COPD were on average 8 years older ($p<0.001$) than the patients with CHF. Other demographic variables did not differ significantly between the groups. The proportions of severely and moderately severely affected patients in each group were comparable ($\chi^2=0.01$, $p=0.91$).

Table 3.1 Demographic variables and clinical characteristics of patients with COPD and patients with CHF

	COPD N = 56 Mean	 SD	CHF N = 65 Mean	 SD	Difference between groups p-value
Age (years)	67.8	8.5	60.0	10.2	.001[a]
Gender (% female)	32.1		29.2		n.s.
Educational level (%)					n.s.
Primary	46.4		29.2		
Lower vocational	30.4		43.1		
Secondary/intermediate vocational	14.3		21.5		
Higher vocational/university	8.9		6.2		
Marital status (% with partner)	87.3		79.7		n.s.
FEV_1 (litres)	1.5	0.7			
FEV_1 (%pred)	49.2	16.6			
FVC (litres)	3.4	0.9			
LVEF (%)			28.9	9.2	
NYHA class (%)					
I			33.8		
II			35.4		
III			27.7		
IV			3.1		
Illness severity (%)					n.s.
Moderately severe	41.8		42.9		
Severe	58.2		57.1		
Smoking (%)					n.s.
Smokers	23.2		18.5		
Former smokers	69.6		69.2		
No smokers (never)	7.2		12.3		
Pack-years (years)	34.6	21.1	28.3	24.5	n.s.
Illness duration (years)	9.6	8.0	7.8	8.2	n.s.

n.s. = not significant

[a]) t value = 4.5

Differences between patients with COPD and CHF in QoL and personal control
Table 3.2 shows the unadjusted mean scores for QoL and personal control in both patient groups. After adjustment for age differences between groups, the COPD patients scored significantly lower than the CHF patients in self-reported physical functioning and psychological functioning. No significant differences between the groups were found with respect to social functioning and overall QoL. With relation to perceptions of personal control, the groups only differed significantly in perceived health competence: patients with COPD reported lower perceived health competence than patients with CHF.

Table 3.2 Differences in QoL (Rand-36) and perceptions of personal control between patients with COPD and patients with CHF

	COPD Mean[a]	SD	CHF Mean[a]	SD	Mean difference	95% CI	p-value[b]
Quality of life							
Physical functioning	40.5	26.7	54.8	27.1	-14.3	-24.0 to -4.6	.03[c]
Social functioning	66.7	28.7	71.2	26.0	-4.4	-14.3 to 5.4	n.s.
Psychological functioning	70.1	20.8	76.1	16.4	-6.0	-12.8 to .9	.04[d]
Overall QoL	6.0	1.5	6.1	1.9	-.1	-.8 to .5	n.s.
Personal control							
Mastery	22.3	4.3	23.7	3.7	-1.4	-2.8 to .1	n.s.
Perceived health competence	24.6	3.9	27.7	4.1	-3.2	-4.6 to -1.7	.001[e]
Self-efficacy *control symptoms*	19.1	2.9	19.4	2.8	-.3	-1.4 to .8	n.s.
Self-efficacy *maintain function*	7.0	2.0	8.0	2.6	-1.0	-1.8 to -.1	n.s.

n.s. = not significant

[a]) unadjusted means (uncorrected for age differences between groups); [b]) adjusted p-values

Analysis of variance between groups: [c]) F-value = 4.6; [d]) F-value = 4.3; [e]) F-value = 12.8

Relationships between illness severity, personal control, and self-reported physical functioning

Table 3.3 shows Pearson's correlation coefficients for the relationships between self-reported physical functioning with illness severity and personal control variables. In both COPD and CHF patients, self-reported physical functioning was significantly related to mastery and self-efficacy *maintain function*, whereas physical functioning was not significantly related to self-efficacy *control symptoms*. For the CHF patients, self-reported physical functioning was also significantly related to perceived health competence ($r = 0.50$, $p < 0.001$).

Furthermore, in neither of the groups was illness severity significantly related to physical functioning. Illness severity was not significantly related to most of the variables of personal control in COPD patients. For CHF patients, significant correlations were found between illness severity and self-efficacy *maintain function* ($r = -0.36$, $p < 0.05$).

Table 3.3 Pearson's correlation coefficients of illness severity, physical functioning (Rand-36) and perceptions of personal control for patients with COPD and patients with CHF

		Physical functioning	Mastery	Perceived health competence	Self-efficacy *control symptoms*	Self-efficacy *maintain function*
Illness severity	COPD	-.14	.09	-.09	.03	-.12
	CHF	-.16	-.13	-.07	-.00	-.36*
	entire group	**-.14**	**-.01**	**-.07**	**.02**	**-.24***
QoL						
Physical functioning	COPD		.32*	.23	.14	.60***
	CHF		.28*	.50***	.18	.48**
	entire group		**.32****	**.39*****	**.17**	**.53*****
Personal control						
Mastery	COPD			.40**	.23	.38**
	CHF			.41**	.12	.35*
	entire group			**.42*****	**.18**	**.37*****
Perceived health competence	COPD				.18	.60***
	CHF				.27	.40**
	entire group				**.23***	**.49*****
Self-efficacy *control symptoms*	COPD					.23
	CHF					.35*
	entire group					**.30****

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

Contributions of illness severity and personal control to physical functioning

Table 3.4 shows the results of the regression analysis of self-reported physical functioning on illness severity and perceptions of personal control in the entire group of patients with COPD and CHF. In the first step, the diagnosis variable (COPD vs. CHF) was entered into the analysis, which revealed a significant relationship with self-reported physical functioning. Second, age was entered, after which the diagnosis variable still showed a significant contribution to the explanation of physical functioning. This indicates that the difference between the groups in self-reported physical functioning cannot be explained entirely by age alone, but that diagnosis-related factors remain contributing factors in the explanation of physical functioning after adjustment for age. Third, illness severity was entered, which also contributed significantly to self-reported physical functioning. After illness severity was entered, the contribution of diagnosis to physical functioning remained significant. In the last step of the regression analysis, mastery, perceived health competence, and self-efficacy subscales *control symptoms* and *maintain function* were entered into the analysis. Once all personal control variables had been entered, only self-efficacy *maintain function* contributed significantly to the explanation of self-reported physical functioning.

Table 3.4 Regression analysis of physical functioning (Rand-36) on illness severity and perceptions of personal control for the entire group of patients with COPD (N = 56) and CHF (N = 65)

		Physical functioning			
	Predictors	B	SE B	β	R^2
Step 1	Diagnosis (COPD vs. CHF)	14.31	4.91	$.26^{**}$	.07
Step 2	Diagnosis (COPD vs. CHF)	11.37	5.30	$.21^{*}$	
	Age	-.38	.26	-.14	.08
Step 3	Diagnosis (COPD vs. CHF)	12.17	5.30	$.22^{*}$	
	Age	-.28	.26	-.10	
	Illness severity	-9.80	4.91	$-.18^{*}$	.11
Step 4	Diagnosis (COPD vs. CHF)	4.00	5.27	.07	
	Age	-.05	.27	-.02	
	Illness severity	-1.68	5.06	-.03	
	Mastery	.68	.66	.10	
	Perceived health competence	.80	.70	.12	
	Self-efficacy *control function*	-.05	.88	-.01	
	Self-efficacy *maintain function*	4.84	1.25	$.42^{***}$	.32

$^{*}p < .05$; $^{**}p < .01$; $^{***}p < .001$

Discussion

This study demonstrated that both disease-specific and generic factors related to differences in diagnosis, illness severity and self-efficacy in particular were related to self-reported physical functioning. However, diagnosis and illness severity did not explain additional variance of self-reported physical functioning after the personal control variables were entered into the analysis. Apparently, although patients with COPD and CHF differed with respect to their level of self-reported physical functioning, the factors that contributed to physical functioning were comparable in both groups.

In the first steps of the regression analysis, both diagnosis and illness severity were related to self-reported physical functioning. Differences in diagnosis may be interpreted as the specific limitations and symptoms caused by each of the illnesses, such as coughing and the production of sputum for patients with COPD, and fatigue and oedema for patients with CHF. Patients with COPD reported worse physical functioning than CHF patients. Furthermore, patients in the severe group manifested worse physical functioning than patients who were moderately ill.

After the personal control variables had been entered into the equation, only self-efficacy *maintain function* contributed significantly to the explanation of self-reported physical functioning. Our model hypothesised independent effects of diagnosis and illness severity on physical functioning as well as an effect through perceptions of personal control. The results of this study partly support the model we hypothesised, since diagnosis and illness severity were initially related to self-reported physical functioning but no longer contributed after self-efficacy was entered. The relationship of diagnosis and illness severity with physical functioning was probably mediated by perceptions of self-efficacy, as suggested by earlier research[30].

Patients with more self-efficacy *maintain function* reported better physical functioning. Self-efficacy *maintain function* indicates the confidence people have to be able to perform physical exercise. Since both self-efficacy *maintain function* and the physical subscale of the Rand-36 measure the perceptions of patients regarding their physical functioning, this association seems rather straightforward. Nevertheless, the Rand-36 assesses daily activities in a rather objective way by specifically describing the activities and asking for the extent to which patients experience limitations in these activities. Moreover, previous research has also found relationships between self-efficacy and more objective physical performance[19;31], which supports the notion that self-efficacy is indeed related to physical functioning. Perceived health competence and mastery did not contribute significantly to the explanation of self-reported physical functioning. Remarkably, these findings indicate that the relationship between personal control and physical functioning holds true for specific perceptions of control concerning health behaviours but not for more general perceptions of personal control over life as a whole.

Another important result of this study is that differences between the groups were found for the physical and psychological functioning QoL domains. CHF patients reported significantly better results for physical and psychological functioning than the COPD patients, after correction for age differences between the groups.

The COPD patients in this study were more impaired with respect to daily activities, such as walking or climbing stairs, and reported more psychological problems, such as a depressed mood. Although differences between the groups were found in the extent to which QoL domains were affected, both COPD and CHF patients scored much lower than healthy people of the same age with respect to physical functioning and social functioning[24]. These results are consistent with the low FEV_1 and LVEF means of the COPD and CHF patients in this study, which indicate that these patient groups are quite disabled.

In this study, a measure of illness severity was created on the basis of the FEV_1%pred for COPD and the LVEF for CHF, which was not significantly related to the physical domain of QoL of the patients. This finding is consistent with earlier studies, which showed that objective measures of pulmonary function and ejection fraction were not correlated with QoL[32;33]. Variables other than the objective physical measures, for example exercise tolerance, and psychological factors, such as anxiety or depression, are probably important correlates of the physical domain of QoL of the patients.

This study has some limitations. First, as the study has a cross-sectional design, the causal relationships between the variables in the study cannot be ascertained and, moreover, this study does not provide insight into the longitudinal relationships between illness severity, personal control, and physical functioning. Consequently, it cannot be determined whether self-efficacy affects self-reported physical functioning or vice versa. Second, the CHF patients who refused to participate in this study were somewhat older on average than the patients who did participate, which may have led to selection bias. The COPD patients in this study were on average 8 years older. Therefore, all results in this study have been corrected for age differences between the groups. Third, in this study, physical functioning was assessed by means of a self-report measure. Previous research has uncovered discrepancies between self-reported physical functioning and more objective, performance-based measures of physical functioning[34]. Unfortunately, in this study no data were available to compare self-reported and objectively measured physical functioning. Fourth, the cut-off points for the illness severity variable we chose for COPD (FEV_1%pred < 50%) and for CHF (LVEF < 30%) are rather arbitrary, making group comparison debatable. However, instead of using the median scores as cut-off points, we chose the cut-off scores mentioned in the literature[20-22].

One implication of this study, important for medical practice, is that physical functioning is not only related to the clinical characteristics of patients with COPD and CHF, but more importantly also to the patients' perceptions of self-efficacy. However, a causal relationship between self-efficacy and physical functioning cannot be determined on the basis of our results, which would be an interesting focus for future studies. In the treatment of patients with COPD and CHF, enhancing health-promoting behaviours is important as well as improving physical functioning, since these behaviours are necessary in the management of both illnesses. Higher self-efficacy has been associated with healthier behaviours, such as smoking cessation[17], more physical exercise and greater training achievements[31]. Consequently, interventions should not only aim at improving physical functioning but also at enhancing COPD and CHF patients' perceptions of self-efficacy. Rehabilitation programmes in particular have been found to be an appropriate intervention to enhance both self-efficacy and physical functioning[19;31].

To conclude, although there are differences between the groups in the extent to which physical functioning is affected, similar factors, namely illness severity and self-efficacy, contribute to the explanation of self-reported physical functioning. For both COPD and CHF, self-efficacy *maintain function* displayed the strongest relationship with physical functioning. We suggest that not only improving physical functioning, but also enhancing perceptions of self-efficacy should be important aims in the treatment of patients with COPD and CHF.

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Reference List

1 Gosker HR, Lencer NHMK, Franssen FME, Van der Vusse GJ, Wouters EFM, Schols AMW. Striking similarities in systemic factors contributing to decreased exercise capacity in patients with severe chronic heart failure or COPD. Chest 2003; 123: 1416-1424.

2 Juenger J, Schellberg D, Kraemer S, Haunstetter A, Zugck C, Herzog W, Haass M. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. Heart 2002; 87: 235-241.

3 Stavem K, Lossius MI, Kvien TK, Guldvog B. The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. Qual Life Res 2000; 9: 865-871.

4 Hamilton AL, Killian KJ, Summers E, Jones NL. Muscle strength, symptom intensity, and exercise capacity in patients with cardiorespiratory disorders. Am J Respir Crit Care Med 1995; 152: 2021-2031.

5 Suurmeijer TPBM, Reuvekamp M, Aldenkamp B, Overweg J, Sie O. Quality of life in epilepsy: multidimensional profile and underlying latent dimensions. J Epilepsy 1998; 11: 84-96.

6 Kempen GIJM, Ormel J, Brilman EI, Relyveld J. Adaptive responses among Dutch elderly: the impact of eight chronic medical conditions on health-related quality of life. Am J Public Health 1997; 87: 38-44.

7 Stewart AL, Greenfield S, Hays RD, Wells K, Rogers WH, Berry SD, McGlynn EA, Ware JE. Functional status and well-being of patients with chronic conditions: results from the Medical Outcomes Study. JAMA 1989; 262: 907-913.

8 Arnold R, Ranchor AV, Sanderman R, Kempen GIJM, Ormel J, Suurmeijer TPBM. The relative contribution of domains of quality of life to overall quality of life for different chronic diseases. Qual Life Res 2004; 13: 883-896.

9 Gurin P, Gurin G, Morrison BM. Personal and ideological aspects of internal and external control. Soc Psychol 1978; 41: 275-296.

10 Helgeson VS. Moderators of the relation between perceived control and adjustment to chronic illness. J Pers Soc Psychol 1992; 63: 656-666.

11 Skinner EA. A guide to constructs of control. J Pers Soc Psychol 1996; 71: 549-570.

12 Yates BC, Belknap DC. Predictors of physical functioning after a cardiac event. Heart Lung 1991; 20: 383-390.

13 Pearlin LI, Lieberman MA, Menaghan EG, Mullan JT. The stress process. J Health Soc Behav 1981; 22: 337-356.

14 Kempen GIJM, Sanderman R, Miedema I, Meyboom-de Jong B, Ormel J. Functional decline after congestive heart failure and acute myocardial infarction and the impact of psychological attributes. A prospective study. Qual Life Res 2000; 9: 439-450.

15 Smith MS, Wallston K, Smith C. The development and validation of the Perceived Health Competence Scale. Health Educ Res 1995; 10: 51-64.

16 Gebhardt WA, van der Doef MP, Paul LB. The Revised Health Hardiness Inventory (RRHI-24): psychometric properties and relationship with self-reported health and health behavior in two Dutch samples. Health Educ Res 2001; 16: 579-592.

17 Meland E, Maeland JG, Laerum E. The importance of self-efficacy in cardiovascular risk factor change. Scand J Public Health 1999; 27: 11-17.

18 Gifford AL, Bormann JE, Shively MJ, Wright BC, Richman DD, Bozzette SA. Predictors of self-reported adherence and plasma HIV concentrations in patients on multidrug antiretroviral regimens. J Acquir Immune Defic Syndr 2000; 23: 386-395.

19 Lox CL, Freehill AJ. Impact of pulmonary rehabilitation on self-efficacy, quality of life, and exercise tolerance. Rehab Psychol 1999; 44: 208-221.

20 Pauwels RA, Buist AS, Ma P, Jenkins CR, Hurd SS. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. National Heart, Lung, and Blood Institute and World Health Organization Global Initiative for Chronic Obstructive Lung Disease (GOLD): executive summary. Respir Care 2001; 46: 798-825.

21 Priori SG, Aliot E, Blomstrom-Lundqvist C, Bossaert L, Breithardt G, Brugada P, Camm JA, Cappato R, Cobbe SM, Di Mario C, Maron BJ, McKenna WJ, Pedersen AK, Ravens U, Schwartz PJ, Trusz-Gluza M, Vardas P, Wellens HJ, Zipes DP. Update of the guidelines on sudden cardiac death of the European Society of Cardiology. Eur Heart J 2003; 24: 13-15.

22 Brodie BR, Stuckey TD, Hansen C, Muncy D. Intra-aortic balloon counterpulsation before primary percutaneous transluminal coronary angioplasty reduces catheterization laboratory events in high-risk patients with acute myocardial infarction. Am J Cardiol 1999; 84: 18-23.

23 Ware JE, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36) : I. Conceptual framework and item selection. Med Care 1992; 30: 473-483.

24 Van der Zee K, Sanderman R, Heyink JW, De Haes HCJM. Psychometric qualities of the RAND 36-item Health Survey 1.0: a multidimensional measure of general health status. Int J Behav Med 1996; 3: 104-122.

25 Cantril H. Discovering people's aspirations: the method used. In: Cantril H, ed. The pattern of human concerns. New Brunswick, NJ: Rutgers University Press, 1965: 21-29.
26 Pearlin LI, Schooler C. The structure of coping. J Health Soc Behav 1978; 19: 2-21.
27 Sullivan MD, LaCroix AZ, Russo J, Katon WJ. Self-efficacy and self-reported functional status in coronary heart disease: a six-month prospective study. Psychosom Med 1998; 60: 473-478.
28 United Nations Educational Scientific and Cultural Organization. International Standard Classification of Education (ISCED). Paris, France: UNESCO, 1976.
29 Ranchor AV, Bouma J, Sanderman R. Vulnerability and social class: differential patterns of personality and social support over the social class. Pers Indiv Dif 1996; 20: 229-237.
30 Kohler CL, Fish L, Greene PG. The relationship of perceived self-efficacy to quality of life in chronic obstructive pulmonary disease. Health Psychol 2002; 21: 610-614.
31 Ewart CK. Role of physical self-efficacy in recovery from heart attack. In: Schwarzer R, ed. Self-efficacy: thought control of action. Washington, DC, US: Hemisphere Publishing Corp., 1992: 287-304.
32 Jones PW. Health status measurement in chronic obstructive pulmonary disease. Thorax 2001; 56: 880-887.
33 Rector TS, Johnson G, Dunkman WB, Daniels G, Farrell L, Henrick A, Smith B, Cohn JN. Evaluation by patients with heart failure of the effects of enalapril compared with hydralazine plus isosorbide dinitrate on quality of life. V-HeFT II. The V-HeFT VA Cooperative Studies Group. Circulation 1993; 87: VI71-VI77.
34 Kempen GIJM, Steverink N, Ormel J, Deeg DJH. The assessment of ADL among frail elderly in an interview survey: self-report versus performance-based tests and determinants of discrepancies. J Gerontol 1996; 51B: P254-P260.

4

The relative contribution of domains of quality of life to overall quality of life for different chronic diseases

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Abstract

Objective

This study examined the contribution of the quality of life (QoL) domains physical, social and psychological functioning to the explanation of overall QoL. Various disorders may differentially affect QoL domains due to disease-specific factors and, consequently, the relationship between QoL domains and overall QoL may vary between diseases. We therefore studied this relationship for several diseases as well as the differential impact of these diseases on QoL.

Methods

The present study had a cross-sectional design. We selected patients (aged 57 years and older) with one of the following eight chronic medical conditions: lung disorder, heart condition, hypertension, diabetes mellitus, back problems, rheumatoid arthritis, migraine, or dermatological disorders. The total group of respondents included 1457 patients and 1851 healthy subjects.

Results

Regression analyses showed that the domain of psychological functioning contributed to overall QoL for all disorders, while physical and social functioning contributed to overall QoL for some disorders. Differences were found between most patient groups and healthy subjects with respect to physical functioning and social functioning; with respect to psychological functioning some groups differed from the healthy group. Explanations for the findings and implications for clinical practice are discussed.

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Introduction

In the last few decades, quality of life (QoL) has become an important outcome measure in both social scientific studies and medical trials[1]. The World Health Organization Quality of Life assessment (WHOQOL) group has defined QoL as 'Individuals' perception of their position in life in the context of the culture and the value system in which they live and in relation to their goals, expectations, standards and concerns'[2]. The WHOQOL definition of QoL focuses attention on the patient's perspective on QoL and assumes an evaluation of several life domains by the patient[3;4]. This definition of QoL has influenced the definitions used in many other studies[1;4-6]. For example, Gill et al.[6] refer to QoL as a 'uniquely personal perception, denoting the way that individual patients feel about their health status and/or non-medical aspects of their lives'. Despite the influence of the WHOQOL definition of QoL, operationalisation of QoL still varies across different studies[7].

Different conceptualisations of QoL have been used, ranging from the general to the more specific[4]. General definitions refer to QoL as the perception of life in general and are conceptually different from health-related QoL, which represents health-related problems in several life domains. Health-related QoL can address disease-specific issues and more generic health-related problems[8]. There are different ways to hierarchically order concepts of QoL, for example in generic- and disease-specific measures of health-related QoL[9]. Furthermore, a distinction has been made between global QoL, the underlying dimensions of QoL and the components each dimension consists of[10;11].

Spilker's hierarchical QoL model[1] ranged from highly general to more specific. This model included overall QoL and separate domains of QoL, as well as a third level covering specific aspects of each domain. For example, measures of anxiety or depression are specific aspects of the domain of psychological functioning; participation in social activities can give an impression of social functioning, whereas functional limitations or activities of daily living are part of the physical domain of QoL. The overall assessment of QoL, defined as 'an individual's overall satisfaction with life, and one's general sense of personal well-being'[1] covers the first level of Spilker's model[5]. This level can be interpreted as a global impression of the overall QoL of patients and corresponds to the WHOQOL definition of QoL. The separate domains of QoL form the second level in Spilker's model. The most widely used domains of QoL are psychological, social and physical functioning. Some studies add other domains of QoL, for example, somatic sensation and occupational function[12], economic status[1], cognitive functioning, personal productivity and intimacy[5]. In general, physical, social and psychological functioning are assumed to reflect QoL rather well. Finally, the third level of Spilker's model consists of the specific aspects of each domain of QoL.

Spilker's model assumes that QoL variables at a lower level determine QoL variables at a higher level[13]. Although this notion is appealing, thus far, little empirical research has been conducted to assess the relations between lower level assessments of QoL and higher level assessments (i.e. overall QoL). From a theoretical point of view, this might be of importance, since it provides insight into the concept of QoL. As follows from Spilker's model, the distinction between measuring functional status on domains of QoL (Spilker's level 2) and a more general perception of QoL (Spilker's level 1) is relevant. Two issues illustrate the distinction between both levels of QoL. First, measuring functional status provides detailed information about the consequences of an illness and makes it possible to determine which domains have been affected by the illness and to what extent[14]. Patients' overall perception of QoL, on the other hand, may be more resistant to change and therefore less applicable to measure changes in the patients' condition as a consequence of illness. This hypothesis has been confirmed by Cummins[15], who proposed that people, due to their ability to adapt to changing factors in their environment, try to maintain a stable level of well-being. Second, domains of QoL probably do not fully cover the QoL of patients. An overall judgement of QoL, on the other hand, requires patients to evaluate several life domains and to combine the weightings of these domains into a 'generic value judgement' of life in general[4]. Therefore, such an overall judgement may better reflect patients' QoL.

In the present study, we focused on the contribution of the domains of QoL, i.e. physical, social and psychological functioning, to overall QoL. Consequently, the purpose of this study was to investigate the extent to which physical, social and psychological functioning explained overall QoL. In this study, we only measured the first and second levels of Spilker's model, since the literature shows great consensus concerning the conceptualisation of these levels of QoL. Specifically, we studied (a) whether physical, social and psychological functioning contributed differentially to overall QoL, and (b) to what extent these domains together explained overall QoL.

Since different diseases may have a differential effect on the functioning of patients in domains of QoL, we studied the relationship between domains of QoL and overall QoL within several disease groups. Only a few studies have compared disorders with respect to QoL[16-22]. Differences among disorders may concern the specific domains which have been affected, as well as the extent to which specific domains have been affected by the illness. Consequently, the contribution of the specific domains to overall QoL may differ between diseases. In the literature, some support has been found for the notion that disorders differentially affect domains of QoL[16;19;20]. Most studies agree that chronic medical conditions have a strong negative effect on physical functioning[21]. The effects of medical conditions on the psychological functioning of patients with a long-term illness are less straightforward. Whereas some studies did find differences in psychological functioning[22] between patients with a chronic disorder and healthy subjects, other studies found no differences in psychological functioning in patients with or without a chronic condition[17]. Therefore, it is important to compare several disorders with respect to QoL, since previous studies found differences in functioning between disorders on domains of QoL. As a result of disease-specific factors, such as specific symptoms or limitations, different medical disorders may have a differential impact on the domains of QoL and, consequently, the contribution of separate domains to overall QoL may vary in different groups of patients.

Methods

The present study was based on data collected in the Groningen Longitudinal Aging Study (GLAS). GLAS was a population-based prospective follow-up study of the psychological and social determinants of disease, functional disability, well-being and utilisation of care in older people[21;23-27]. The primary objective of this study was to identify the psychosocial factors that influence the trajectory of QoL, independently or in interplay with disease-related factors. In 1993, a baseline assessment was carried out in a sample of 5279 persons of 57 years and older. Since then, several cohort studies have been conducted in which participants who experienced a particular disorder were followed for 12 months after the onset of the disorder.

Source Population

The source population consisted of late middle-aged and older people, living independently or in adapted housing for elderly people in the north of the Netherlands. The study population comprised 8723 persons aged 57 and older on 1 January 1993, and all participants were registered with general practitioners participating in the Morbidity Registration Network Groningen (RNG). The RNG consists of 27 general practitioners who register every doctor-patient encounter in a computerised health information system; all these general practitioners participated in the study. In the Netherlands, approximately 99% of the non-institutionalised elderly are registered with a general practitioner who keeps full medical records. By letter, general practitioners asked potential participants for permission to provide the GLAS research team with their names and addresses. A total of 1937 patients refused (22%). Of the remaining 6786 patients, 1277 declined participation when contacted by the research team, and 152 had died or left the practice by the time contact was initiated. Another 78 participants were excluded because of severe cognitive impairments at baseline (Mini-Mental State Examination score of 16 or lower)[27]. Useful baseline data were available for 5279 research participants (62%; 5279 / (8723 – 152)). With respect to subject non-response bias, non-response was not random but associated with female gender and with higher age. Objectives, design and matters of representativeness of the GLAS study have been described earlier[21;23]. The results showed no evidence of non-response bias relevant to the issues addressed in our study. The GLAS baseline assessment was carried out in 1993 and consisted of an interview and a mailed questionnaire. The research participants were interviewed face-to-face in their homes (N = 4792) or by telephone (N = 487) by well-trained middle-aged women who were not acquainted with the interviewees.

Patients and healthy subjects

In this study, patients with specified diseases and a healthy subgroup were selected from the baseline sample. We selected the eight chronic medical conditions that were most prevalent in the baseline sample by means of a checklist. In order to study the separate effect of each specified illness on the QoL of the patients involved, only patients with one disorder were included; thus, patients with co-morbidity (N=1690) were excluded from the analyses.

We selected patients who were diagnosed with one of the following eight different chronic diseases: lung disorder (N=159), heart condition (N=284), hypertension (N=405), diabetes mellitus (N=102), back problems for at least 3 months (N=117), rheumatoid arthritis or other joint complaints (N=227), chronic headache or migraine (N=77), and serious dermatological disorders such as psoriasis and eczema (N=86). The total group of patients we selected from the baseline assessment consisted of 1457 patients. In addition to the eight different groups of patients, one healthy group of 1851 persons without any chronic illness was included in the study.

Measures

Data were collected by means of semi-structured interviews and self-report questionnaires. These self-report questionnaires were partly administered during the interview and partly filled in directly after the interview.

Chronic conditions

A checklist of 19 chronic medical conditions was used in the interview part of the baseline data collection to identify the different patient groups in the study. Participants indicated whether they had any of these conditions in the 12 months prior to the interview. The Dutch Central Office for Statistics used the same procedure in its Health Survey Interview[28]. To reduce potential reporting bias by patients, only 'active' conditions were included – 'active' refers to conditions for which a general practitioner or a specialist had been consulted or medicines had been used during the 12 months prior to the interview[21]. The conditions were: asthma or chronic bronchitis, pulmonary emphysema, heart condition, hypertension, (consequences of) stroke, diabetes mellitus, back problems for at least 3 months or slipped disc, rheumatoid arthritis or other joint complaints, migraine or chronic headache, serious dermatological disorders such as psoriasis and eczema, kidney disease, cancer, thyroid gland disorder, stomach ulcer, multiple sclerosis, other diseases of the nervous system such as Parkinson's disease or epilepsy, liver disease or gallstones, prostate disease, and leg ulcer. Results from other studies showed that these were usually conditions for which acceptable agreement was observed between self-reports and medical registrations[29;30]. The present study concerned patients with the eight most prevalent chronic medical conditions together with a group of healthy subjects.

Specific domains of QoL

Physical functioning (six items), *social functioning* (one item) and *psychological functioning* (five items) were measured by the MOS (Medical Outcome Study) Short-Form General Health Survey (SF-20)[31]. Physical functioning and psychological functioning were measured during the interview part of the baseline assessment. Social functioning was measured by means of self-report. The physical functioning subscale measured the extent to which health interfered with activities such as climbing stairs and going for a walk. The social functioning scale assessed the interference of health with normal social activities such as visiting friends or family. Psychological functioning measured mood, including anxiety and depression, and well-being. All subscales varied from 0 to 100; higher scores indicated better functioning.

Overall QoL

Cantril's ladder measured overall QoL[32]. This scale was part of the questionnaire which patients filled in after the interview and measured overall QoL on a scale ranging from 0 to 10. Patients answered the following question: 'Here is a picture of a ladder. Suppose we say that the top of the ladder represents the best possible life for you and the bottom represents the worst possible life for you. Where on the ladder do you feel you personally stand at the present time?'

Socio-demographic variables

The socio-demographic variables sex, age, marital status and educational level were assessed during the baseline interview. Marital status consisted of two categories, namely with or without a partner. Educational level consisted of six categories, which were reduced to four, ranging from less educated to highly educated[33]. Recent studies support the view that socio-demographic factors may to some extent contribute to the explanation of overall QoL. Sprangers et al.[16] reported that, independent of the kind of illness, older age, being female, being less educated and living without a partner were related to a lower QoL. Therefore, the analyses in this study were corrected for these demographic variables.

Data analysis

First, we calculated mean scores and standard deviations for all domains of QoL and overall QoL to study the differences between the groups under study. Differences in mean scores were statistically tested with analysis of variances and Dunnetts T3 test for post-hoc analysis. We performed regression analyses of the QoL domains and overall QoL on the demographic variables age, sex, marital status and educational level, to control for these background variables. The standardised residuals were used as dependent variables for the analysis of variance to test the differences between the healthy group and the different patient groups. Since inequality of variance was found, we performed Dunnetts T3 post-hoc test. We then performed bivariate correlation analyses to study the associations between domains of QoL and overall QoL. Third, multiple regression analyses were performed to assess the relative contribution of the several domains of QoL to overall QoL. On the basis of the theoretical model applied in a previous study[4], we supposed that a physical disorder not only directly affects patients' overall QoL, but also through an effect on physical, social, and eventually, psychological functioning. Therefore, we performed a hierarchical regression analysis. First, to adjust for the influence of socio-demographic characteristics, the variables age, sex, marital status and educational level were brought into the analysis. In the next step, the QoL domains were entered hierarchically into the analysis: The domain of physical functioning was first entered, followed by social functioning and, finally, psychological functioning. The outcome measure was overall QoL measured by Cantril's ladder. Entering the QoL domains hierarchically into the analysis meant that the contribution of each domain was corrected for the contributions of the other domains. The beta coefficients of the three domains in the final regression model show the independent (direct) relationships of the separate domains with overall QoL, after all the variables have been entered into the analysis.

Results

Socio-demographic variables

Table 4.1 shows the scores on demographic variables for each separate medical condition and for the healthy group. Significant differences were found among the groups with respect to age, gender, educational level and marital status, which is not unexpected considering the large sample size. The largest difference between the groups was found with respect to gender. In the group with a heart condition relatively more patients were male. In the groups with migraine, rheumatoid arthritis, back problems, diabetes mellitus or hypertension, on the other hand, relatively more patients were female.

Differences between patient groups and healthy subjects in QoL domains

Table 4.2 shows the mean scores of the groups of patients and the healthy group for the MOS scales. The mean scores on domains of QoL in the patient groups and healthy subjects were compared, in order to study the differential effects of the medical conditions on the physical, social and psychological functioning of the patients.

Various patient groups, with the exception of patients with hypertension, diabetes mellitus and dermatological problems, scored significantly lower on *physical* functioning than did healthy subjects. Regarding *social* functioning, significantly lower scores were found for patients with lung disorders, a heart condition, back problems, rheumatoid arthritis and migraine compared with healthy subjects. Furthermore, patients with lung disorders and migraine reported a lower *psychological* functioning than did healthy subjects; remarkably, no other patient groups differed significantly from the healthy group in this respect.

To summarise these results, patients with lung disorders and those with migraine reported lower functioning than did healthy subjects in all domains of QoL, whereas, in contrast, patients with hypertension, diabetes mellitus or dermatological disorders did not differ in any of the QoL domains compared to healthy subjects. Patients with heart conditions, back problems and rheumatoid arthritis scored lower than the healthy subjects in the physical and social domains of QoL.

Differences between patient groups and healthy subjects in overall QoL

With respect to overall QoL measured by Cantril's ladder, only patients with lung disorders and migraine reported a significantly lower overall QoL than healthy sub-

Table 4.1 Demographic characteristics for patients with chronic medical conditions and healthy subjects

	Chronic medical conditions																		
	Healthy subjects N = 1851		Lung disorder N = 159		Heart condition N = 284		Hyper-tension N = 405		Diabetes mellitus N = 102		Back problems N = 117		Rheumatoid arthritis N = 227		Migraine N = 77		Dermatological disorders N = 86		
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Statistics
Age (years)	68.5	8.1	69.9	7.7	71.3	7.9	69.2	7.5	71.3	7.8	68.2	8.2	69.9	8.4	65.5	7.6	67.3	8.2	F = 8.1*** [b]
Sex (%)																			
Male	48.7		54.7		66.2		34.1		36.3		32.5		28.6		26.0		48.8		χ^2 = 133.5*** [c]
Female	51.3		45.3		33.8		65.9		63.7		67.5		71.4		74.0		51.2		
Educational level (%)[a]																			
I	32.1		45.3		32.4		35.8		49.0		29.0		37.2		33.8		25.6		χ^2 = 45.6** [c]
II	27.3		28.9		26.0		29.6		20.6		30.8		28.8		24.7		27.9		
III	28.7		22.0		28.2		23.7		23.5		32.5		22.5		28.5		31.4		
IV	11.9		3.8		13.4		10.9		6.9		7.7		11.5		13.0		15.1		
Marital status (%)																			
No partner	28.3		32.7		26.4		34.1		36.3		35.0		37.0		22.1		26.7		χ^2 = 19.6* [c]
With partner	71.7		67.3		73.6		65.9		63.7		65.0		63.0		77.9		73.3		

a) I = Primary school; II = lower vocational training; III = secondary school/intermediate vocational training; IV = higher vocational training/university

b) Analysis of variance between groups

c) χ^2 tests: * $p < .05$; ** $p < .01$; *** $p < .001$

jects. This is in accordance with the findings mentioned above, since these patients also reported a lower functioning in all QoL domains. All other patient groups did not differ significantly from the healthy group with respect to overall QoL.

Correlations between QoL domains and overall QoL

Pearson's correlation coefficients were calculated between domains of QoL and overall QoL for each separate group. Table 4.3 shows the correlation coefficients for the patient groups and healthy subjects. Correlation coefficients varied from 0.16 to 0.54; the strongest associations were found for patients with migraine between social functioning and overall QoL ($r=0.53$, $p<0.01$) and psychological functioning with overall QoL ($r=0.54$, $p<0.01$). For patients with dermatological disorders, physical functioning and overall QoL were not significantly correlated ($r=0.16$, n.s.).

Contributions of QoL domains to overall QoL

First, correlation coefficients were computed for each domain of QoL with the other domains, which, for reasons of space, are not reported in a table but just discussed here. The strongest correlation coefficients were found for social functioning and physical functioning ($r=0.45$, $p<0.01$), psychological functioning and overall QoL ($r=0.41$, $p<0.01$), and social functioning and psychological functioning ($r=0.32$, $p<0.01$). Somewhat smaller correlation coefficients were found for social functioning and overall QoL ($r=0.30$, $p<0.01$), physical functioning and overall QoL ($r=0.26$, $p<0.01$), and physical functioning and psychological functioning ($r=0.22$, $p<0.01$).

Second, regression analyses were performed to study the independent contribution of the domains of QoL to overall QoL for each medical condition and for the healthy subjects. Table 4.4 presents the independent contributions of the QoL domains in the final regression model after all domains have been entered into the analysis. The regression analyses, described more extensively in the analysis section, were performed separately for each group of patients and the healthy subjects, following the same procedure.

In the final regression model, an important part of the variance of overall QoL for all medical conditions was explained by the domain of psychological functioning (β coefficients ranging from 0.24 to 0.41). For all disorders as well as for the healthy subjects, psychological functioning was related to overall QoL. Social functioning was independently related to overall QoL for healthy subjects ($\beta=0.13$, $p<0.001$) and patients with back problems ($\beta=0.25$, $p<0.05$), rheumatoid arthritis ($\beta=0.21$, $p<0.01$) and migraine ($\beta=0.32$, $p<0.01$). Physical functioning contributed to the explanation of overall QoL for patients with lung disorders ($\beta=0.28$, $p<0.01$) and hypertension ($\beta=0.12$, $p<0.05$) as well as for the healthy subjects ($\beta=0.08$, $p<0.01$). Since the group of healthy subjects included a larger number of subjects than the patient groups, smaller beta coefficients were found to be significant in the healthy group.

The variances explained by demographic variables together with the three domains of QoL did not differ much among the various disorders. For most disorders the percentages of explained variances ranged from approximately 20% for patients with heart conditions, hypertension, diabetes, dermatological disorders and

Table 4.2 QoL (MOS Short-Form Questionnaire and Cantril's ladder) of patients with chronic medical conditions and healthy subjects

	Chronic medical conditions																	
	Healthy subjects N = 1851		Lung disorder N = 159		Heart condition N = 284		Hyper-tension N = 405		Diabetes mellitus N = 102		Back problems N = 117		Rheumatoid arthritis N = 227		Migraine N = 77		Dermatological disorders N = 86	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Quality of life																		
Physical functioning	81.20	23.22	64.05^{c}	28.66	66.37^{c}	27.44	75.99	26.09	69.95	29.76	55.84^{c}	25.27	60.13^{c}	28.48	73.46^{a}	25.85	81.59	21.85
Social functioning	89.30	20.67	76.75^{c}	27.48	81.44^{c}	23.61	88.36	20.80	84.57	24.47	78.58^{b}	24.60	77.73^{c}	25.65	80.55^{a}	23.56	90.95	15.02
Psychological functioning	80.40	17.11	74.01^{c}	19.55	78.52	17.99	77.84	16.06	77.41	20.39	74.07	18.75	76.62	17.44	70.11^{b}	20.23	76.09	19.23
Overall QoL	7.70	1.42	7.14^{c}	1.53	7.46	1.46	7.64	1.33	7.39	1.39	7.34	1.50	7.41	1.55	7.05^{b}	1.45	7.63	1.25

Analysis of variance between each condition and healthy subjects, after correction for age, gender, educational level, and marital status (unadjusted means are displayed)

^{a}) $p < .05$; ^{b}) $p < .01$; ^{c}) $p < .001$

Tabel 4.3 Pearson's correlation coefficients of QoL domains (MOS Short-Form Questionnaire) and overall QoL (Cantril's ladder) of patients with chronic medical conditions and healthy subjects

	Chronic medical conditions								
	Healthy subjects	Lung disorder	Heart condition	Hyper-tension	Diabetes mellitus	Back problems	Rheumatoid arthritis	Migraine	Dermatological disorders
Quality of life									
Physical functioning	.20**	.40**	.24**	.20**	.34**	.33**	.24**	.25*	.16
Social functioning	.26**	.36**	.31**	.24**	.28**	.38**	.34**	.53**	.35**
Psychological functioning	.41**	.43**	.39**	.40**	.30**	.42**	.42**	.54**	.38**

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

Table 4.4 Regression analysis of overall QoL (Cantril's ladder) on domains of QoL (MOS Short-Form Questionnaire) for patients with chronic medical conditions and healthy subjects, after corrections for demographic variables

	Chronic medical conditions																	
	Healthy subjects		Lung disorder		Heart condition		Hyper-tension		Diabetes mellitus		Back problems		Rheumatoid arthritis		Migraine		Dermatological disorders	
	β	ΔR²	β	ΔR²	β	ΔR²	β	ΔR²	β	ΔR²	β	ΔR²	β	ΔR²	β	ΔR²	β	ΔR²
Demographic characteristics																		
Age	.01		-.07		.05		.05		.07		-.02		$.15^a$		.19		-.02	
Sex	$.08^b$		.11		.13		$.12^a$		.17		.06		.04		.09		.14	
Marital status	$.07^b$		.07		.08		$.13^a$		.17		-.03		$.14^a$		.13		.14	
Educational level	.02	.03	.06	.08	.06	.02	-.03	.04	.07	.05	.06	.03	-.02	.05	.11	.12	.15	.10
Quality of life																		
Physical functioning	$.08^b$	.03	$.28^b$	.11	.12	.05	$.12^a$	.02	.19	.09	.16	.08	.10	.06	.13	.03	-.03	.00
Social functioning	$.13^c$	.04	.07	.03	.14	.05	.08	.03	.14	.02	$.25^a$	.08	$.21^b$	.06	$.32^b$	.18	.19	.08
Psychological functioning	$.35^c$	.10	$.38^c$	.11	$.32^c$	.08	$.37^c$	.12	$.24^a$	.05	$.33^b$	.09	$.34^c$	.10	$.41^b$	.11	$.27^a$	.05
Total R²		.20		.33		.20		.21		.21		.28		.27		.44		.23

a) p < .05; b) p < .01; c) p < .001

healthy subjects to approximately 30% for patients with lung disorders, back problems and rheumatoid arthritis. Remarkably, for patients with migraine, the QoL domains and demographic variables explained 44% of the variance of overall QoL.

To sum up, the results of the regression analyses showed that the domains of QoL differed with respect to their contribution to overall QoL, yet the independent contribution of the domains depends on the type of disorder. In the final model, psychological functioning was independently related to overall QoL for all patient groups. For patients with back problems, rheumatoid arthritis and migraine, social functioning also maintained a direct effect on overall QoL in the final model. In the groups of patients with lung disorders and hypertension physical functioning was also related to overall QoL. Thus, although physical and social functioning were related to overall QoL for some disorders, psychological functioning showed the strongest independent relationship with overall QoL for all patient groups and healthy subjects.

Discussion

The main focus of the present study was to examine the contribution of QoL domains to the explanation of overall QoL. The results of the regression analyses showed that the domain of psychological functioning contributed to overall QoL for all disorders and for the healthy subjects. Only for some disorders, i.e. lung disorder, hypertension, back problems, rheumatoid arthritis and migraine, did physical or social functioning contribute independently to overall QoL. For the healthy subjects, the physical, social and psychological domains all contributed significantly to overall QoL, although this may be due to sample size. Furthermore, we studied the differences between several medical conditions and a healthy group in functioning on QoL domains and overall QoL. The results showed that most patient groups reported a lower physical functioning than the healthy subjects, with the exception of patients with hypertension, diabetes mellitus and dermatological disorders. With respect to social functioning, five of the eight patient groups were impaired, whereas with respect to psychological functioning only patients with lung disorders and migraine differed from the healthy group. These results are consistent with earlier studies that found small differences between patients and healthy subjects with respect to psychological and social functioning[17;34]. Stein et al.[34], for example, suggested that diagnosis as a variable is not a good predictor for social and psychological outcomes. Apparently, although there are differences between disorders with respect to the domains of QoL that have been affected, most disorders had an effect on physical functioning.

This study shows that the separate QoL domains made a limited contribution to the explanation of overall QoL. Impairments in one or more of the domains of QoL do not automatically result in an impairment of overall QoL. Measuring domains of QoL and overall QoL seem to be two different ways to study the impact of an illness on the lives of patients. For example, we found that physical functioning contributed to overall QoL for only a few disorders, whereas most patient groups did show a lower physical functioning than the healthy group did. Furthermore, few patient groups were impaired with respect to psychological functioning compared to the healthy subjects, while psychological functioning contributed to the explanation of overall QoL for all disorders. On the other hand, for patients with lung disorders and migraine, who were impaired with respect to all three QoL domains, the three domains of QoL explained the largest amount of variance of overall QoL. When two domains of QoL were affected, namely in patients with a heart condition, back problems or rheumatoid arthritis, somewhat less variance of overall QoL was explained. For the patient groups that were impaired with respect to only one domain or were not impaired at all, the amount of variance explained by the three domains of QoL did not differ from that of the healthy group. It seems as if the separate domains of QoL contribute most to the explanation of overall QoL when the impact of the disease is profound, i.e., when it extends to all domains of QoL.

With respect to overall QoL, it appeared that most chronically ill patients did not differ from the healthy subjects. Comparable results were found by Cummins[35;36], who reported a 'gold standard' for subjective well-being which he had found for many different people with different nationalities. According to Cummins[36], people tend to maintain a certain level of well-being, regardless of changes in their environment. Only when these changes exceed a certain threshold will environmental factors affect the subjective well-being of people[15]. The finding that most patient groups did not differ from the healthy group supports this hypothesis of 'homeostasis' and shows that patients eventually adapt to their illness to a certain extent. Patients with lung disorders and migraine differed from the healthy subjects for all three domains of QoL. This may have led to them exceeding the threshold of homeostasis and made it no longer possible for them to maintain a normal level of well-being and, in our case, overall QoL.

The results showed that more diseases affected the physical domain of QoL than the psychological domain. However, we also found that psychological functioning in particular and physical functioning to a lesser degree contributed to the explanation of overall QoL. Similar results have been found by Suurmeijer et al.[4], who also reported that psychosocial variables explained more variance of a judgement of overall QoL than clinical variables. Our findings support a hierarchical relationship between the QoL domains, which we assumed in the regression model we applied. Moreover, we found moderately strong correlations between physical functioning on the one hand and psychological and social functioning on the other, which underlines this assumption.

Since the primary aim of our study was to examine the relative contribution of the separate QoL domains to overall QoL, in order to avoid bias due to co-morbidity, we decided to select patients with only one medical condition. By doing so, it was also possible to study the specific effects of a single disorder on the QoL domains of the patients involved. On the other hand, this may have led to selection bias: Most elderly people have more than one co-morbid condition and, consequently, we may have selected the somewhat healthier elderly people from the sample. Therefore, the findings concerning the impact of disease on QoL should be interpreted cautiously.

This study has a few shortcomings. First, patients with prevalent disorders of unknown duration have been included. Therefore, within groups, patients probably varied with respect to the duration of their illness: Some patients in the advanced stages of their illness may already have adapted to their illness, whereas other patients were at the beginning of the process. Depending on the kind of illness, patients in advanced stages of the illness may already have deteriorated significantly, whereas patients at the beginning of the course of an illness may have been much healthier. Therefore, the patient groups in the study were probably heterogeneous. Second, the data used in this study are cross-sectional and therefore do not provide insight into the longitudinal effects of functioning on domains and overall QoL and a subsequent effect of domains on overall QoL. Physical, social and psychological functioning are probably subject to fluctuations in time, for example due to the course of the illness. Therefore, the relationships between domains and overall QoL may also change over time. It might be interesting to study the relationship between changes in functioning in QoL domains with overall QoL in patients with different illnesses. Furthermore, since the data are cross-sectional, it is not possible to test statistically the hierarchical ordering of the physical, social and psychological domains. We assumed that physical functioning affects psychological functioning through social functioning, but we cannot exclude the possibility of inverse relationships or feedback loops. In addition, the hierarchy among the QoL domains may differ across disorders. For example, conditions mainly characterised by motor or vitality problems, such as back problems or rheumatoid arthritis, probably first affect the physical functioning of patients, whereas conditions like dermatological disorders, which affect patients' appearance, may first have an effect on social functioning.

A subject that needs further attention concerns the result that the amount of variance explained by the three domains of QoL was not very large. This can partly be explained by the fact that both the QoL domains and overall QoL were measured in a relatively simple way; for instance, overall QoL was measured by one single item. We measured QoL on only two levels of Spilker's model[1], which means that no underlying factors of the three QoL domains were discriminated. Moreover, we measured the three domains of QoL by means of the SF-20, which measures the effects of a disease on functioning. As a consequence, this measure focuses only on those aspects of QoL that are related to health. We realise that the aspects of physical, social and psychological functioning we measured do not entirely explain overall QoL, since health probably plays a relatively small part in QoL[37]. Other important factors than the three major domains of QoL contribute to overall QoL[37]. Although, in general, these three domains of QoL are studied to represent QoL, factors such as personal resources or life events are likely to affect patients' overall QoL.

By measuring functioning on domains of QoL, additional information about other factors that affect the overall QoL of patients may have been overlooked. Verkerk et al.[38] provided a theoretical explanation that offers a wider perspective on the assessment of QoL. Their model includes the capability of people, which refers to the opportunity people have to achieve a certain desired situation, despite their functioning on specific life domains. For example, although a disabled person may not be able to perform certain activities by himself, he can manage to have a satisfying social life by asking friends to accompany him. This patient is more capable than other patients who are not able to change their situation, which consequently may affect their QoL. This explanation is consistent with Cummins's hypothesis of homeostasis, namely that people try to maintain a stable level of well-being, regardless of small environmental changes[15].

Another important issue concerns the judgement of patients of their overall QoL. The assumption has been made that patients make judgements about different aspects of their lives and combine these into a general judgement about the overall quality of their lives. The question is whether patients actually do make such a general judgement. Campbell et al.[39] state that 'life as a whole is a concept of such breadth that few people are accustomed to thinking of their situation in such a way'. According to Rogerson[7], the interpretation of overall judgements of QoL is rather difficult, while the same results can be explained by different underlying factors. It may well be that people have different operationalisations in mind, and even within subjects, these operationalisations may change over time due to changing priorities during the course of life or due to changing life circumstances, such as certain life-events.

The result of this study that domains of QoL and an overall judgement of QoL imply two different ways of looking at QoL may be of consequence for health professionals, since measuring QoL can be helpful in determining the right treatment for a specific patient. In this case, the choice for one of the measures to assess the QoL of a patient depends on the kind of information needed. For example, when a doctor wants to know if his patient's physical functioning is good enough to participate in a rehabilitation programme, he needs detailed information about the physical domain of QoL. When a health professional is interested in patients' overall well-being as a result of a particular treatment, asking for a judgement of overall QoL can be sufficient. Another finding that may be important for clinical practice is that, in this study, patients with lung disorders and migraine were much worse off than the other patient groups in this study. With respect to physical functioning as well as social and psychological functioning, these patients reported a lower functioning than the healthy subjects did. This implies that these patients may benefit from a more multidisciplinary treatment, for example aimed at the psychological consequences of these illnesses, rather than just paying attention to the medical aspects of these illnesses.

A more conceptual implication of this study concerns the definition of QoL: The terms 'Quality of Life' or 'health-related Quality of Life' are used for domains of QoL as well as general perceptions of QoL, and therefore, the use of this term leads to confusion. A good solution may be to refer to functioning in domains of QoL as physical, social and psychological functioning and reserve the term 'QoL' for more general, subjective perceptions about life as a whole.

To conclude, this study assessed the relationship between domains of QoL and overall QoL. Previous studies have noted a distinction between both perspectives on QoL, namely a general conceptualisation of QoL or dividing QoL in several components[1;4;7]. However, the present study has advanced this discussion by assessing the relative contribution of the domains of QoL and showing that the three domains of

QoL do not explain the total variance of overall QoL. Furthermore, this study has compared patients with various kinds of disorders, which has only been performed by a few other studies[16]. It would be interesting to study the functioning of patients in domains of QoL and overall QoL longitudinally to investigate whether the contributions of the domains to overall QoL change over time and whether these contributions are affected by the course of the illness.

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Reference List

1 Spilker B. Introduction to the field of quality of life trials. In: Spilker B, ed. Quality of life assessments in clinical trials. New York: Raven Press, 1990: 3-10.
2 Kuyken W, Orley J, Power M, Herrman H, Schofield H, Murphy B, Metelko Z, Szabo S, Pibernik-Okanovic M. The world health organization Quality of Life assessment (WHO-QOL): position paper from the world health organization. Soc Sci Med 1995; 41: 1403-1409.
3 Suurmeijer TPBM, Waltz M, Moum T, Guillemin F, Van Sonderen FLP, Briançon S, Sanderman R, Van den Heuvel WJ. Quality of Life profiles in the first years of rheumatoid arthritis: results from the EURIDISS longitudinal study. Arthritis Rheum 2001; 45: 111-121.
4 Suurmeijer TPBM, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. Epilepsia 2001; 42: 1160-1168.
5 Shumaker SA, Anderson RT, Czajkowski SM. Psychological tests and scales. In: Spilker B, ed. Quality of life assessments in clinical trials. New York: Raven Press, 1990: 95-113.
6 Gill TM, Feinstein AR. A critical appraisal of the quality of Quality of Life measurements. JAMA 1994; 272: 619-626.
7 Rogerson RJ. Environmental and health-related quality of life: conceptual and methodological similarities. Soc Sci Med 1995; 41: 1373-1382.
8 Frisch MB. Improving mental and physical health care through quality of life therapy and assessment. In: Diener E, Rahtz DR, eds. Advances in quality of life theory and research. Boston: Kluwer Academic Publishers, 2000: 207-241.
9 Guyatt GH. Measurement of health-related quality of life in heart failure. Ir J Psychol 1994; 15: 148-163.
10 Spilker B, Revicki D. Taxonomy of quality of life. In: Spilker B, ed. Quality of life and pharmacoeconomics in clinical trials. Philadelphia: Lippincott-Raven Publishers, 1996: 25-31.

11 Fries JF, Singh G. The hierarchy of patient outcomes. In: Spilker B, ed. Quality of life and pharmacoeconomics in clinical trials. Philadelphia: Lippincott-Raven Publishers, 1996: 33-40.

12 Schipper H, Clinch J, Powell V. Definitions and conceptual issues. In: Spilker B, ed. Quality of life assessments in clinical trials. New York: Raven Press, 1990: 11-24.

13 Suurmeijer TPBM, Reuvekamp M, Aldenkamp B, Overweg J, Sie O. Quality of life in epilepsy: multidimensional profile and underlying latent dimensions. J Epilepsy 1998; 11: 84-96.

14 Leventhal H, Colman S. Quality of life: a process view. Psychol Health 1997; 12: 753-767.

15 Cummins RA. Objective and subjective quality of life: an interactive model. Soc Indic Res 2000; 52: 55-72.

16 Sprangers AG, De Regt EB, Andries F, Van Agt HME, Bijl RV, De Boer JB, Foets M, Hoeymans N, Jacobs AE, Kempen GIJM, Miedema HS, Tijhuis MAR, De Haes HCJM. Which chronic conditions are associated with better or poorer quality of life? J Clin Epidemiol 2000; 53: 895-907.

17 Cassileth BR, Lusk EJ, Strouse TB, Miller DS, Brown LL, Cross PA, Tenaglia AN. Psychosocial status in chronic illness: a comparative analysis of six diagnostic groups. N Engl J Med 1984; 311: 506-511.

18 Felton BJ, Revenson TA, Hinrichsen GA. Stress and coping in the explanation of psychological adjustment among chronically ill adults. Soc Sci Med 1984; 18: 889-898.

19 Pollock SE, Christian BJ, Sands D. Responses to chronic illness: analysis of psychological and physiological adaptation. Nurs Res 1990; 39: 300-304.

20 Stavem K, Lossius MI, Kvien TK, Guldvog B. The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. Qual Life Res 2000; 9: 865-871.

21 Kempen GIJM, Ormel J, Brilman EI, Relyveld J. Adaptive responses among Dutch elderly: the impact of eight chronic medical conditions on health-related quality of life. Am J Public Health 1997; 87: 38-44.

22 Stewart AL, Greenfield S, Hays RD, Wells K, Rogers WH, Berry SD, McGlynn EA, Ware JE. Functional status and well-being of patients with chronic conditions: results from the Medical Outcomes Study. JAMA 1989; 262: 907-913.

23 Kempen GIJM, Jelicic M, Ormel J. Personality, chronic medical morbidity, and health-related quality of life among older persons. Health Psychol 1997; 16: 539-546.

24 Kempen GIJM, Miedema I, Van den Bos GAM, Ormel J. Relationship of domain-specific measures of health to perceived overall health among older subjects. J Clin Epidemiol 1998; 51: 11-18.

25 Ormel J, Kempen GIJM, Penninx BWJH, Brilman EI, Beekman ATF, Van Sonderen FLP. Chronic medical conditions and mental health in old people: disability and psychosocial resources mediate specific mental health effects. Psychol Med 1997; 27: 1065-1077.

26 Ormel J, Kempen GIJM, Deeg DJH, Brilman EI, Van Sonderen FLP, Relyveld J. Functioning, well-being, and health perception in late middle-aged and older people: comparing the effects of depressive symptoms and chronic medical conditions. J Am Geriatr Soc 1998; 46: 39-48.

27 Folstein MF, Folstein SE, McHugh PR. Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975; 12: 189-198.

28 Centraal Bureau voor de Statistiek. Gezondheids-enquete 1989. Voorburg/Heerlen: CBS, 1989.

29 Van den Bos GAM. The burden of chronic diseases in terms of disability, use of health care and healthy life expectancies. Eur J Public Health 1995; 5: 29-34.

30 Kriegsman DMW, Penninx BWJH, Van Eijk JTM, Boeke AJP, Deeg DJH. Self-reports and general practioner information on the presence of chronic diseases in community dwelling elderly. A study on the accuracy of patients' self-reports and on determinants of inaccuracy. J Clin Epidemiol 1996; 49: 1407-1417.

31 Stewart AL, Hays RD, Ware JE. The MOS short-form general health survey: reliability and validity in a patient population. Med Care 1988; 26: 724-735.

32 Cantril H. Discovering people's aspirations: the method used. In: Cantril H, ed. The pattern of human concerns. New Brunswick, NJ: Rutgers University Press, 1965: 21-29.

33 Centraal Bureau voor de Statistiek. Standaard Onderwijs Indeling 1978; uiteenzetting en verantwoording. 1987 ed. Voorburg: CBS, 1987.

34 Stein REK, Jessop DJ. What diagnosis does not tell: the case for a noncategorical approach to chronic illness in childhood. Soc Sci Med 1989; 29: 769-778.

35 Cummins RA. On the trail of the gold standard for subjective well-being. Soc Indic Res 1995; 35: 179-200.

36 Cummins RA. The second approximation to an international standard for life satisfaction. Soc Indic Res 1998; 43: 307-334.

37 Hunt SM. The problem of quality of life [editorial]. Qual Life Res 1997; 6: 205-212.

38 Verkerk MA, Busschbach JJV, Karssing ED. Health-related quality of life research and the capability approach of Amartya Sen. Qual Life Res 2001; 10: 49-55.

39 Campbell A, Converse PE, Rodgers WL. The quality of American life. New York: Russell Sage Foundation, 1976.

5

Dyspnoea in relation to quality of life domains and overall quality of life in patients with Chronic Obstructive Pulmonary Disease and Chronic Heart Failure

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Abstract

Objective

This study compared patients with Chronic Obstructive Pulmonary Disease (COPD) and Chronic systolic Heart Failure (CHF) and investigated whether dyspnoea symptoms affect overall Quality of Life (QoL) through the physical, social, and psychological domains of QoL in these patients.

Methods

Consecutive patients with COPD and CHF were included from the outpatient clinics of a university hospital, a general hospital and a rehabilitation centre. Ninety-five patients diagnosed with COPD (aged 65.0±9.3), with an $FEV_1 < 70\%$ were included and compared with 90 patients diagnosed with CHF (aged 59.6±10.0), with an $LVEF < 45\%$. All patients completed a questionnaire measuring symptoms of dyspnoea and QoL (Rand-36 Health Survey, Cantril's ladder).

Results

COPD patients scored significantly worse than the CHF patients on dyspnoea and self-reported physical and psychological functioning. The results of the LISREL analyses showed that dyspnoea affected overall QoL for COPD and CHF patients both directly and indirectly through self-reported physical functioning. Self-reported physical functioning only indirectly affected overall QoL through an effect on social functioning. For COPD patients, psychological functioning also affected overall QoL and mediated the relationship between social functioning and overall QoL.

Conclusion

This study showed that the relationship between symptoms of dyspnoea and overall QoL was mediated by the physical and social domains of QoL in both COPD and CHF.

Submitted

Introduction

Chronic Obstructive Pulmonary Disease (COPD) and Chronic systolic Heart Failure (CHF) are major public health problems[1;2], due to their large impact on morbidity and mortality in Western society[1;3]. With respect to clinical characteristics, COPD and CHF are comparable to a certain extent: both are progressive illnesses characterised by breathlessness and diminished capacity for exercise[4]. In addition, both have a serious impact on functional status[5] and on the quality of life (QoL) of the patients[3;6-8].

Although COPD and CHF patients experience comparable limitations and symptoms to a certain degree, the underlying causes of these symptoms are quite different and, therefore, the psychological impact of these diseases may be different. Consequently, there may be differences between COPD and CHF patients in the extent to which their QoL is affected[9]. Nevertheless, the processes through which the QoL of patients with COPD and CHF is affected may be comparable since both are chronic and deteriorating illnesses, and the patients experience partially comparable symptoms, such as breathlessness[4].

In recent years, interest in QoL has been on the increasing, both as an outcome measure in clinical and psychological studies[10;11] and in the treatment of chronically ill patients[3;12-14]. Various conceptualisations of QoL, from general to specific, have been used[15;16]. Spilker[10], one of the few researchers involved, has incorporated these various operationalisations of QoL into a hierarchical model that distinguishes between global QoL, the separate domains of QoL, and the specific components of each domain[17;18]. The overall evaluation of QoL, defined as 'an individual's overall satisfaction with life, and one's general sense of personal well-being'[13], covers the first level of Spilker's model[10]. The second level in Spilker's model consists of the separate QoL domains, of which physical, social, and psychological functioning are the most widely used. The third level of Spilker's model consists of the specific aspects of each QoL domain. For example, limitations in daily activities or illness-related symptoms are specific aspects of the physical domain of QoL. In QoL research, operationalisation varies in parallel to these levels of specificity[15], from global QoL to the specific symptoms caused by an illness.

One of the assumptions of Spilker's model is that variables at the most specific level of QoL, such as symptoms (Spilker's level 3), affect the domains of QoL (level 2) and eventually the overall level of QoL (level 1)[19]. A prior study investigated the extent to which QoL domains at the second level of Spilker's model contributed to overall QoL (Spilker's level 1) for several chronic disorders[9]. That study revealed that the psychological domain of QoL contributed independently to overall QoL for all chronic disorders. Physical or social functioning contributed to overall QoL for only some disorders. This study extends this issue by adding variables from the third level of Spilker's model to the analyses. Symptoms of dyspnoea were thus focused on since these are major symptoms for both COPD and CHF patients. The aim of this study was twofold: first, we studied whether symptoms of dyspnoea affect overall QoL through the physical, social, and psychological QoL domains. Second, the relationship between dyspnoea and overall QoL was investigated to determine whether it was similar for COPD and CHF patients. In doing so, a QoL model that included the three levels of specificity of Spilker's model was tested, but a hierarchical ordering among the QoL domains at level 2 of Spilker's model was also hypothesised.

A hierarchical ordering of QoL domains was supported by Suurmeijer et al.[16] and Arnold et al.[9], based on a study by Pearlin et al[20]. Pearlin hypothesised that the relationship between physical functioning and overall QoL is partly mediated by social and psychological functioning. Suurmeijer et al.[16] found that variables of the psychological domain contributed most to the explanation of overall QoL, although they hypothesised that the effects of the medical and social variables probably run through psychological functioning. The order in which QoL domains are affected probably depends on the characteristics of a particular illness, and may differ for patients with chronic and acute illnesses. In acute illnesses, patients may be diagnosed before the illness in question has affected their physical functioning and therefore the impact of the diagnosis may be what determines their quality of life. Consequently, in an acute illness, diagnosis may first affect the psychological domain of QoL before the patients experience limitations to their physical functioning. Patients with COPD and CHF, on the other hand, first start experiencing symptoms such as dyspnoea, which in turn cause limitations to their daily physical functioning. Consequently, this may affect the social activities the patients can participate in and ultimately their psychological functioning. Therefore, in this study it was hypothesised that the physical domain, which is primarily affected by symptoms of dyspnoea, affects overall QoL through social and psychological functioning. Figure 5.1 shows the full model, which was tested on both COPD and CHF patients. We expected to find comparable QoL models for both COPD and CHF.

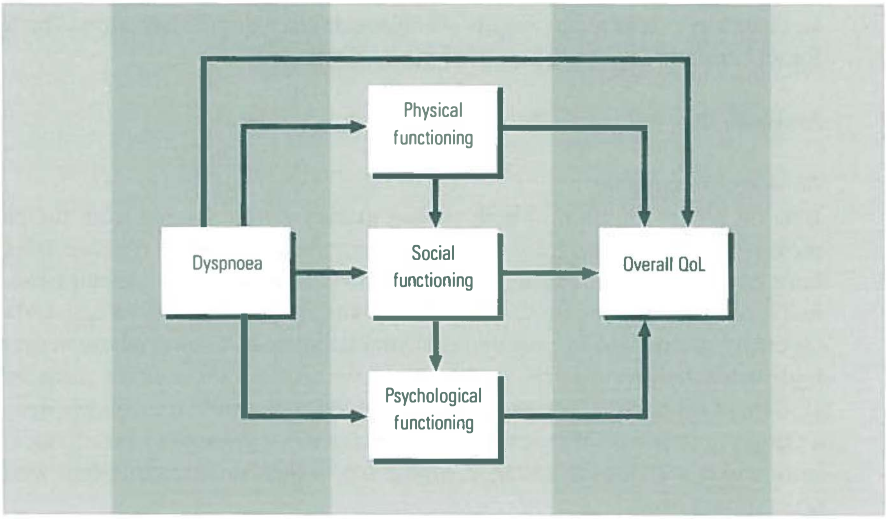

Figure 5.1 Theoretical model, based on Spilker[10;17], of relationships between dyspnoea, QoL domains and overall QoL

Methods

Patients and study design

Consecutive patients with COPD or CHF were recruited at a university hospital, a general hospital and a university rehabilitation centre from January 2001 to June 2002. Data from the patients in the rehabilitation centre were combined with the data from the patients in the outpatient clinics for both COPD and CHF. In this study, the assessment after the patients had finished their rehabilitation programme was used, because at that moment the patients were more comparable with the patients in the outpatient clinic than before they attended the rehabilitation programme. Preliminary analyses revealed no significant differences between patients from the rehabilitation centre and patients from the outpatient clinics with respect to physical, social, and psychological functioning, overall QoL, and symptoms of dyspnoea. Furthermore, correlation coefficients between QoL domains and overall QoL were comparable for patients in rehabilitation and patients from the outpatient clinics for COPD and CHF.

Eligible patients received written information about the study and an informed consent form. COPD patients were included if they were (1) diagnosed with COPD, (2) registered with a forced expiratory volume in 1 second (FEV_1) of less than 70% of the predicted value, and (3) free from other pulmonary disease. Patients with CHF were included if they were (1) diagnosed with CHF, (2) registered with a left ventricular ejection fraction (LVEF) of less than 45%, and (3) free from other cardiovascular disease. Patients in both groups were aged between 40 and 80 years, free from other serious disease (such as cancer), free from psychiatric problems in the previous year, and fluent in the Dutch language. The study had a cross-sectional design and data were collected by means of self-report mailed questionnaires. The Medical Ethics Committees of both centres approved the study.

Assessments

Clinical characteristics

Data on illness duration in both patient groups were collected from the patients' medical records. A short questionnaire measured the number of illness-related symptoms experienced by the patients over the previous week[21]. This questionnaire, which was originally designed for COPD patients, was adapted for patients with CHF based on the literature[2] and in consultation with cardiologists to incorporate items assessing manifestations of CHF. In this study, we selected those items measuring the amount of dyspnoea experienced at rest and during exercise over the previous week, a symptom of both COPD and CHF. Dyspnoea was measured by two items, ranging from 0 to 6, which were averaged; higher scores indicate that symptoms were more often experienced.

Quality of Life

Three Rand 36-item Health Survey subscales[22;23] were selected for the assessment of QoL, covering the three major domains of QoL: *physical functioning* (10 items), *psychological functioning* (5 items), and *social functioning* (2 items). Physical functioning measures the extent to which health interferes with daily activities such as climbing stairs. Psychological functioning measures mood, including feelings of depression or tension. Social functioning assesses the interference of health with normal social activities such as visiting friends or relatives. All subscales vary from 0 to 100; higher scores indicate better functioning.

Overall QoL was measured on Cantril's ladder[24], a scale ranging from 0 to 10, with higher scores indicating a higher overall QoL. Patients answered the question: 'Here is a picture of a ladder. Suppose the top of the ladder represents the best possible life for you and the bottom represents the worst possible life for you. Where on the ladder do you feel you personally stand at the present time?'

Socio-demographic variables

Age, gender, marital status and educational level were assessed. Educational level was assessed according to the International Standard Classification of Education[25;26], which has six categories that were re-coded into four categories, ranging from lower to higher educated.

Data analysis

First, t-tests and chi-square tests were performed to compare the COPD and CHF patients with respect to demographic characteristics. Second, the differences between the groups in terms of symptoms of dyspnoea, QoL domains and overall QoL were tested by means of analysis of variance, to control for age differences between the groups. Third, bi-variate correlation analyses were performed to study the association of dyspnoea, QoL domains and overall QoL in both patient groups.

Fourth, the theoretical model was tested by means of structural equation modelling (LISREL). LISREL is a multivariate technique designed to study causal relationships between variables and is an elaboration of regression analysis. In order to be able to perform LISREL, two criteria must be met: first, a causal relationship between two variables is known or assumed on the basis of previous research or theoretical considerations. Second, no reciprocal relationships or 'feedback loops' are possible.

The input for structural equation modelling was the correlation matrix (Table 5.3) with the relationships between dyspnoea, QoL domains and overall QoL. Separate analyses were performed for patients with COPD and CHF, in which the same model was tested (displayed in Figure 5.1). Starting with the full model (Figure 5.1), most non-significant paths between the variables were removed one by one to obtain the best-fit and most parsimonious model. Models for both groups were evaluated by examining the parameter estimates and measures of overall fit provided by LISREL.

Results

Patient groups

One hundred and thirty-four COPD patients (86 from the outpatient clinic and 48 in rehabilitation) were asked to participate in the study. In the outpatient clinics, of the 86 potential participants, 19 did not respond and 11 refused. In rehabilitation, of the 48 potential participants, 1 patient died, 1 had an exacerbation, and 7 withdrew from the study before the end of the rehabilitation programme. Patients who were not included in the study did not differ significantly from the participants with respect to age and gender. In total, 95 COPD patients were included in the study (response rate 71%).

In the CHF patient group, 138 patients (110 from the outpatient clinic and 28 in rehabilitation) were invited for the study. Of the 110 potential participants in the outpatient clinic, 45 refused to participate. In rehabilitation, of the 28 potential participants, 3 withdrew from the study before the end of the rehabilitation programme. Patients who were not included did not differ significantly from the participants with respect to gender, but a significant difference was found with respect to age: patients who refused to participate were on average 8 years older than the participants. Ninety CHF patients participated in the study (response rate 65%).

Socio-demographic variables

Table 5.1 shows the demographic variables for the COPD and CHF patients. The COPD patients were on average 5 years older ($p < 0.001$) than the patients with CHF (65.0 against 59.6 respectively). Furthermore, illness duration for COPD patients was on average 3 years longer than for CHF patients (10.2 against 6.5). Other demographic variables did not differ significantly between the groups.

Table 5.1 Demographic variables of patients with COPD and patients with CHF

	COPD N = 95 Mean	SD	CHF N = 90 Mean	SD	Difference between groups p-value
Age (years)	65.0	9.3	59.6	10.0	.001[a]
Gender (% female)	35.8		24.4		n.s.
Educational level (%)					n.s.
Primary	39.0		26.7		
Lower vocational	32.6		35.6		
Secondary/intermediate vocational	15.8		23.3		
Higher vocational/ university	12.6		14.4		
Marital status (% with partner)	86.2		81.8		n.s.
Illness duration (years)	10.2	10.0	6.5	7.9	.01[b]

n.s. = not significant

[a]) differences between groups: t-value = 3.8; [b]) t-value = 2.5

Differences between COPD and CHF in dyspnoea, domains of QoL and overall QoL
Table 5.2 shows the mean scores on dyspnoea, QoL domains and overall QoL for both patient groups. The results, corrected for age differences, show that the COPD patients scored significantly worse than the CHF patients on dyspnoea and self-reported physical and psychological functioning. No significant differences between the groups were found with respect to social functioning and overall QoL.

Table 5.2 Dyspnoea, domains of QoL and overall QoL for patients with COPD and patients with CHF

	COPD		CHF		Difference between groups
	Mean[a]	SD	Mean[a]	SD	p-value[b]
Dyspnoea	2.7	1.1	1.8	1.1	.001[c]
Quality of life					
Physical functioning	38.3	24.7	57.8	26.1	.001[d]
Social functioning	63.6	27.6	69.7	25.2	n.s.
Psychological functioning	69.3	20.8	74.9	16.3	.02[e]
Overall QoL	6.0	1.6	6.2	1.7	n.s.

n.s. = not significant

[a]) unadjusted means (uncorrected for age differences between groups); [b]) adjusted p-values

Analysis of variance between groups: [c]) F value = 28.9; [d]) F value = 20.1; [e]) F value = 5.4

Relationships between dyspnoea, domains of QoL and overall QoL
The input for the structural equation modelling consisted of the correlation matrix as displayed in Table 5.3. The results indicated that all domains of QoL were significantly interrelated for both COPD and CHF patients and also related to overall QoL. Furthermore, higher dyspnoea scores were significantly related to worse scores on QoL domains and overall QoL.

Figures 5.2 and 5.3 show the best fitting models for COPD and CHF. The parameters for goodness of fit indicate a good fit for the model for both COPD and CHF. First, the χ^2 values indicate a good fit for the model ($\chi^2=3.69$, $p=0.30$, $df=3$ for COPD; $\chi^2=4.24$, $p=0.37$, $df=4$ for CHF), although these χ^2 values result to a certain extent from small sample sizes. However, other indices also indicate a good fit for the model: for the Root Mean Square Error of Approximation (RMSEA) a value below 0.05 is supposed to indicate a good fit, although values up to 0.08 are acceptable as well. In both the COPD and the CHF groups, the RMSEA value is lower than 0.08 (RMSEA=0.051 for COPD; RMSEA=0.029 for CHF). The Expected Cross Validation Index (ECVI) is an index that takes both fit and model parsimony into account and therefore prohibits the addition of too many irrelevant parameters to the model[27]. ECVI values should be low; values lower than the ECVI for the saturated model in particular indicate a good fit for the model. This is the case for COPD and CHF in this study (ECVI=0.30 (sat.=0.32) for COPD; ECVI=0.30 (sat. = 0.34) for CHF).

Table 5.3 Pearson's correlation coefficients of dyspnoea, QoL domains and overall QoL for patients with COPD and patients with CHF

		Physical functioning	Social functioning	Psychological functioning	Overall QoL
Dyspnoea	COPD	-.62	-.47	-.35[a]	-.53
	CHF	-.69	-.47	-.34[a]	-.61
Quality of life					
Physical functioning	COPD		.63	.34[a]	.57
	CHF		.53	.30[a]	.60
Social functioning	COPD			.60	.60
	CHF			.65	.65
Psychological functioning	COPD				.50
	CHF				.43

a) $p < .01$; all other correlation coefficients $p < .001$

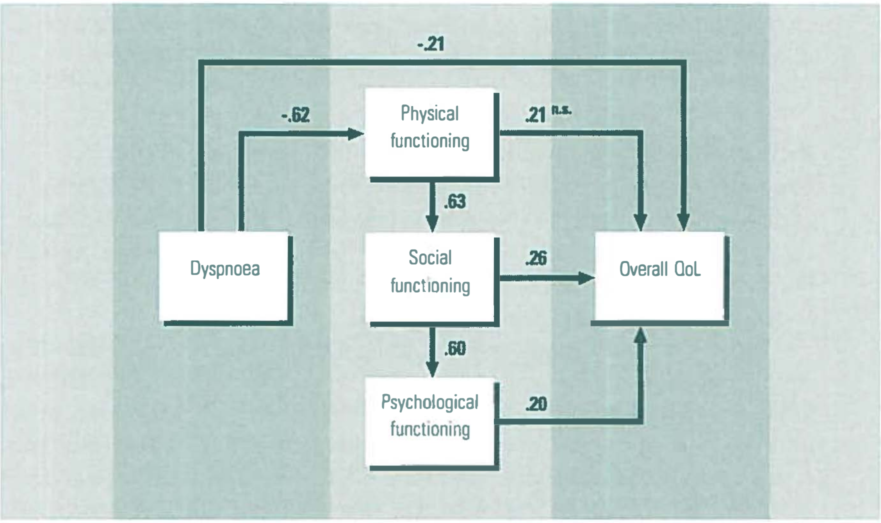

Figure 5.2 Final model of relationships between dyspnoea, QoL domains and overall QoL for patients with COPD

$^{n.s.}$ β is not significant
$\chi^2 = 3.69$ ($p = .30$; df = 3)
RMSEA = .051
ECVI = .30 (sat. = .32)
N = 95

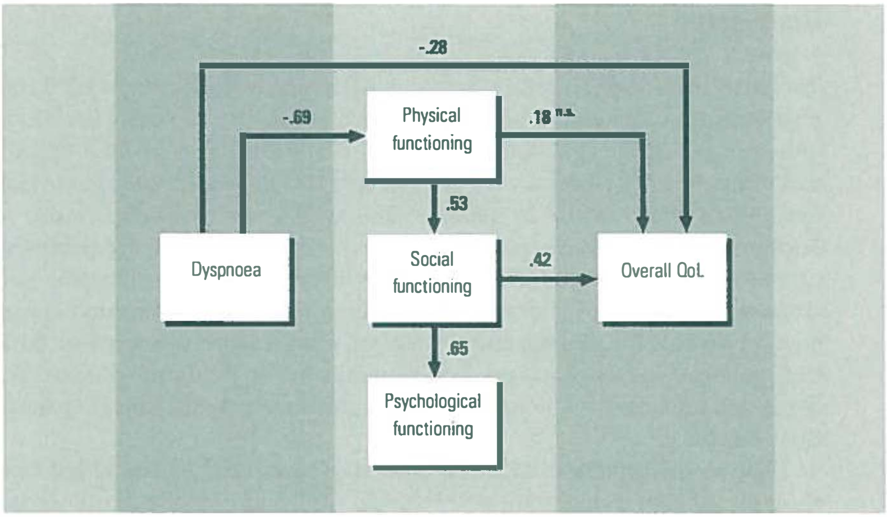

Figure 5.3 Final model of relationships between dyspnoea, QoL domains and overall QoL for patients with CHF

n.s. β is not significant
$\chi^2 = 4.24$ (p = .37; df = 4)
RMSEA = .029
ECVI = .30 (sat. = .34)
N = 90

The models show that dyspnoea affected overall QoL both directly and indirectly, through self-reported physical and social functioning, for COPD and CHF patients. Physical functioning explained overall QoL only indirectly through an effect on social functioning. Although it was not significant, the direct path between physical functioning and overall QoL in both groups was included in the model, since this model provided a better fit for the data. For both COPD and CHF patients, social functioning was directly related to overall QoL. Only for COPD patients was the effect of social functioning on overall QoL through psychological functioning significant. The results support the hypothesis of a mediating effect of social functioning, since direct relationships were found between physical functioning and social functioning, and social functioning with overall QoL.

These results demonstrated that the structural models were nearly identical for patients with COPD and CHF. In both groups, overall QoL was explained by the physical and social domains of QoL and symptoms of dyspnoea. Dyspnoea and social functioning were directly related to overall QoL, whereas self-reported physical functioning, on the other hand, only indirectly affected overall QoL through an effect on social functioning. For COPD patients, psychological functioning also affected overall QoL and mediated the relationship between social functioning and overall QoL.

Discussion

This study investigated whether symptoms of dyspnoea affect overall QoL through the physical, social, and psychological QoL domains, and whether there is a hierarchical ordering among the QoL domains for COPD and CHF patients. We hypothesised that symptoms of dyspnoea were both directly and indirectly related to overall QoL, through an effect on the domains of QoL, which was supported by our results. Furthermore, the results supported a hierarchical ordering of QoL domains in these patient groups: symptoms of dyspnoea only directly affected the physical domain of QoL and not the social and psychological domains. The relationship between QoL domain physical functioning and overall QoL was mediated by social functioning for CHF patients, and social and psychological functioning for COPD patients. The best-fitting and most parsimonious models were reasonably comparable for patients with COPD and CHF.

The model hypothesised in this study was based on the hierarchical QoL models designed in previous studies[9;16;28]. Spilker & Revicki[17] hierarchically ordered the QoL domains somewhat differently from the ordering assumed in our model: they assumed that the symptoms caused by a disease first affect the physical and psychological domains of QoL, which then affect the social domain of QoL. However, the order in which domains of QoL are affected may depend on the characteristics of a particular illness and whether the illness is acute or chronic. Moos & Schaefer[29] argued that serious physical illness may be regarded as a life crisis, to which patients have to adapt. The threatening character of an acute illness is more likely to cause a life crisis than a gradually developing chronic illness, and therefore may affect the QoL domains in a different order than a chronic illness. With respect to COPD and CHF, it was hypothesised that symptoms of breathlessness affect the amount of physical activity the patients can perform (such as walking or cycling), which in turn affects their social activities with friends or family. Eventually, this will lead to deteriorated psychological functioning and a lower overall appreciation of QoL. This hypothesis was supported by the results that dyspnoea symptoms were only directly related to physical functioning, and were not directly related to social and psychological functioning. Furthermore, it was discovered that social functioning for COPD and CHF, and both social and psychological functioning for COPD, did indeed mediate the relationship between physical functioning and overall QoL.

Remarkably, a direct effect of dyspnoea on overall QoL was found. Apparently, the relationship between dyspnoea and overall QoL was not entirely mediated by the three domains of QoL. This may be explained partly by the fact that the Rand-36 does not assess all domains of functioning on which dyspnoea has an important impact. For example, dyspnoea may also have an effect on the amount and quality of sleep the patients get, which in turn may affect the overall QoL of the patients. Furthermore, the Rand-36 is a generic instrument and therefore does not assess illness-specific domains of functioning, which may be relevant in the explanation of overall QoL.

The results of this study showed that not all of the variance of overall QoL was explained by the variables in our model. This may be explained partly by the fact that health-related QoL was focused on assessing the QoL domains and those aspects of QoL that were unrelated to health, such as the economic situation of the patients, were not measured. Dyspnoea and the physical, social, and psychological domains of QoL do not entirely explain overall QoL, as health probably determines QoL to a limited extent[30]. Hunt[30] argues that functional status and symptoms may influence QoL, though they are not synonymous with QoL. This reflects an important issue in QoL research, which is whether QoL should be measured as a whole or through several components that represent the whole[15]. Both are clearly distinct ways of assessing QoL; the choice of a more specific or more general measure of QoL merely depends on the kind of information a researcher might need.

This study has some limitations. First, since this study had a cross-sectional design and all patients had been ill for a fairly long time, whether the QoL domains indeed followed one another chronologically could not be determined. Therefore, it would be interesting to study the relationships between domains of QoL longitudinally in a sample of newly diagnosed patients. Second, in this study, data from patients in the outpatient clinics were combined with the data from patients who had just finished their rehabilitation programme. Therefore, as mentioned previously in the methods section, the possible influence on the results of using data from two different groups was checked, which turned out not to be the case. The advantage of including both sets of patients was that the patients in this study may better represent the total populations of COPD and CHF patients. Third, on average, the CHF patients who refused to participate were eight years older than the participants, which could indicate selection bias. As a result, the COPD patients were on average five years older than the CHF patients. However, since age was not significantly correlated with the outcome measure of this study, the other analyses were not corrected for age differences between the groups.

This study is of theoretical importance because the relationships between the three levels of QoL[10], and in particular the relationship between symptoms of dyspnoea and overall QoL, were investigated. Only a few previous studies have assessed the relationship between symptoms of dyspnoea and overall QoL[31;32], but they did not report consistent results. This study has provided further insight into the process through which symptoms of dyspnoea influence patients' overall QoL. Furthermore, this study contributes to the current knowledge of QoL, as it tested a QoL model in two different patient groups. Although only a few studies have compared patients with different diseases, some studies have shown that the extent to which QoL domains are affected may differ for patients with different diseases[8;9;33-35]. Irrespective of the differences found here between COPD and CHF in functioning on domains of QoL, this study showed that the relationships between symptoms of dyspnoea, QoL domains, and overall QoL are broadly similar for patients with COPD and CHF.

Another theoretical implication is that the results of this study supported Spilker's[10] ordering of QoL into three dimensions of specificity and showed that the more specific levels of QoL do indeed influence the more general levels of QoL. In the literature, there is still disagreement concerning the definition of QoL and the level of specificity at which QoL should be measured[15;16]. This study indicates the importance of assessing QoL at several levels of specificity, since each level contributes to a certain extent to overall QoL. This issue was also noted by a previous study, which concluded that a study of the impact of COPD should not only include the disease-specific aspects, but also the 'overall burden of the disease on everyday functioning and emotional well-being'[36]. Fries & Singh[37] argued that this hierarchical perspective allows researchers to use different instruments for specific aspects or dimensions of QoL, which leads to completeness of the assessment.

The issue that QoL at more specific levels contributes to the general level of QoL may also be relevant for clinical practice. In particular, this study showed that symptoms of dyspnoea directly affect the overall QoL of patients, except for their effect on physical functioning. This may be a directive for patient treatment, since these results imply that improving the patients' QoL at the level of symptoms may lead to a better overall QoL. Furthermore, it is important for a physician to know to what extent dyspnoea and physical functioning lead to limitations in the patients' social activities, since this in turn affects both their psychological functioning and their overall QoL.

To conclude, this study assessed the relationship between symptoms and QoL domains with overall QoL in COPD and CHF patients. This study contributes to QoL research by assessing QoL at three levels of specificity and by studying the relationships between these levels. This study showed that, although only symptoms of dyspnoea and the social QoL domain were directly related to overall QoL, part of the relationship between dyspnoea and overall QoL was mediated by the physical, social, and psychological QoL domains. Another important contribution made by this study is the finding that, although the underlying causes of both diseases are different, the relationships between symptoms, QoL domains and overall QoL are comparable in both diseases. In future research, it would be of interest to study whether this hierarchical ordering of QoL domains is different in patients with more acute, rather than chronic, diseases.

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Reference List

1 Pauwels RA, Buist AS, Ma P, Jenkins CR, Hurd SS. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. National Heart, Lung, and Blood Institute and World Health Organization Global Initiative for Chronic Obstructive Lung Disease (GOLD): executive summary. Respir Care 2001; 46: 798-825.

2 Hunt SA, Baker DW, Chin MH, Cinquegrani MP, Feldman AM, Francis GS, Ganiats TG, Goldstein S, Gregoratos G, Jessup ML, Noble RJ, Packer M, Silver MA, Stevenson LW, Gibbons RJ, Antman EM, Alpert JS, Faxon DP, Fuster V, Gregoratos G, et al. ACC/AHA

guidelines for the evaluation and management of chronic heart failure in the adult: executive summary. Circulation 2001; 104: 2996-3007.

3 Berry C, McMurray J. A review of quality-of-life evaluations in patients with congestive heart failure. Pharmacoeconomics 1999; 16: 247-271.

4 Hamilton AL, Killian KJ, Summers E, Jones NL. Muscle strength, symptom intensity, and exercise capacity in patients with cardiorespiratory disorders. Am J Respir Crit Care Med 1995; 152: 2021-2031.

5 Gosker HR, Lencer NHMK, Franssen FME, Van der Vusse GJ, Wouters EFM, Schols AMW. Striking similarities in systemic factors contributing to decreased exercise capacity in patients with severe chronic heart failure or COPD. Chest 2003; 123: 1416-1424.

6 Ekman I, Fagerberg B, Lundman B. Health-related quality of life and sense of coherence among elderly patients with severe chronic heart failure in comparison with healthy controls. Heart Lung 2002; 31: 94-101.

7 Juenger J, Schellberg D, Kraemer S, Haunstetter A, Zugck C, Herzog W, Haass M. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. Heart 2002; 87: 235-241.

8 Stavem K, Lossius MI, Kvien TK, Guldvog B. The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. Qual Life Res 2000; 9: 865-871.

9 Arnold R, Ranchor AV, Sanderman R, Kempen GIJM, Ormel J, Suurmeijer TPBM. The relative contribution of domains of quality of life to overall quality of life for different chronic diseases. Qual Life Res 2004; 13: 883-896.

10 Spilker B. Introduction to the field of quality of life trials. In: Spilker B, ed. Quality of life assessments in clinical trials. New York: Raven Press, 1990: 3-10.

11 Guyatt GH. Measurement of health-related quality of life in heart failure. Ir J Psychol 1994; 15: 148-163.

12 Frisch MB. Improving mental and physical health care through quality of life therapy and assessment. In: Diener E, Rahtz DR, eds. Advances in quality of life theory and research. Boston: Kluwer Academic Publishers, 2000: 207-241.

13 Shumaker SA, Anderson RT, Czajkowski SM. Psychological tests and scales. In: Spilker B, ed. Quality of life assessments in clinical trials. New York: Raven Press, 1990: 95-113.

14 Barnett DB. Assessment of quality of life. Am J Cardiol 1991; 67: 41C-44C.

15 Rogerson RJ. Environmental and health-related quality of life: conceptual and methodological similarities. Soc Sci Med 1995; 41: 1373-1382.

16 Suurmeijer TPBM, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. Epilepsia 2001; 42: 1160-1168.

17 Spilker B, Revicki D. Taxonomy of quality of life. In: Spilker B, ed. Quality of life and pharmacoeconomics in clinical trials. Philadelphia: Lippincott-Raven Publishers, 1996: 25-31.

18 Schipper H, Clinch J, Powell V. Definitions and conceptual issues. In: Spilker B, ed. Quality of life assessments in clinical trials. New York: Raven Press, 1990: 11-24.

19 Suurmeijer TPBM, Reuvekamp M, Aldenkamp B, Overweg J, Sie O. Quality of life in epilepsy: multidimensional profile and underlying latent dimensions. J Epilepsy 1998; 11: 84-96.

20 Pearlin LI, Aneshensel CS, LeBlanc AJ. The forms and mechanisms of stress proliferation: the case of AIDS caregivers. J Health Soc Behav 1997; 38: 223-236.

21 Van der Molen T, Willemse BMW, Schokker S, Ten Hacken NHT, Postma DS, Juniper EF. Development, validity and responsiveness of the Clinical COPD Questionnaire. Health Qual Life Outcomes [serial online] 2003 Apr 28 [cited 2003 Aug 5];1;[10 screens]. Available from: URL:http://www.hqlo.com/content/1/1/13.

22 Ware JE, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36) : I. Conceptual framework and item selection. Med Care 1992; 30: 473-483.

23 Van der Zee K, Sanderman R, Heyink JW, De Haes HCJM. Psychometric qualities of the RAND 36-item Health Survey 1.0: a multidimensional measure of general health status. Int J Behav Med 1996; 3: 104-122.

24 Cantril H. Discovering people's aspirations: the method used. In: Cantril H, ed. The pattern of human concerns. New Brunswick, NJ: Rutgers University Press, 1965: 21-29.

25 United Nations Educational Scientific and Cultural Organization. International Standard Classification of Education (ISCED). Paris, France: UNESCO, 1976.

26 Ranchor AV, Bouma J, Sanderman R. Vulnerability and social class: differential patterns of personality and social support over the social class. Pers Indiv Dif 1996; 20: 229-237.

27 Browne MW, Cudeck R. Single sample cross-validation indices for covariance structures. Multivariate Behav Res 1989; 24: 445-455.

28 Leventhal H, Colman S. Quality of life: a process view. Psychol Health 1997; 12: 753-767.

29 Moos RH, Schaefer JA. Coping resources and processes: current concepts and measures. In: Goldberger L, Breznitz S, eds. Handbook of stress: theoretical and clinical aspects (2nd ed.). New York, NY, Free Press, 1993: 234-257.

30 Hunt SM. The problem of quality of life [editorial]. Qual Life Res 1997; 6: 205-212.

31 Singh SJ, Sodergren SC, Hyland ME, Williams J, Morgan MDL. A comparison of three disease-specific and two generic health-status measures to evaluate the outcome of pulmonary rehabilitation in COPD. Respir Med 2001; 95: 71-77.

32 Willenheimer R, Erhardt L, Cline C, Rydberg E, Israelsson B. Exercise training in heart failure improves quality of life and exercise capacity. Eur Heart J 1998; 19: 774-781.

33 Pollock SE, Christian BJ, Sands D. Responses to chronic illness: analysis of psychological and physiological adaptation. Nurs Res 1990; 39: 300-304.

34 Sprangers AG, De Regt EB, Andries F, Van Agt HME, Bijl RV, De Boer JB, Foets M, Hoeymans N, Jacobs AE, Kempen GIJM, Miedema HS, Tijhuis MAR, De Haes HCJM. Which chronic conditions are associated with better or poorer quality of life? J Clin Epidemiol 2000; 53: 895-907.

35 Schlenk EA, Erlen JA, Dunbar Jacob J, McDowell J, Engberg S, Sereika SM, Rohay JM, Bernier MJ. Health-related quality of life in chronic disorders: a comparison across studies using the MOS SF-36. Qual Life Res 1998; 7: 57-65.

36 Engstrom CP, Persson LO, Larsson S, Sullivan M. Health-related quality of life in COPD: why both disease-specific and generic measures should be used. Eur Respir J 2001; 18: 69-76.

37 Fries JF, Singh G. The hierarchy of patient outcomes. In: Spilker B, ed. Quality of life and pharmacoeconomics in clinical trials. Philadelphia: Lippincott-Raven Publishers, 1996: 33-40.

6

The relationship between objective and subjective health in patients with Chronic Obstructive Pulmonary Disease and Chronic Heart Failure

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Abstract

Objective

This study investigates the relationship between objective and subjective health parameters in patients with chronic obstructive pulmonary disease (COPD) and patients with chronic heart failure (CHF) by testing Wilson and Cleary's conceptual model of patient outcomes[1]. First, we studied whether the relationship between objective health parameters (FEV_1 for COPD and LVEF for CHF) and general health perceptions was mediated by symptoms of dyspnoea and physical functioning. Second, it was investigated whether perceptions of personal control were related to the health parameters in the model.

Methods

Consecutive patients with COPD and CHF were included from the outpatient clinics of a university hospital and a general hospital, and from a rehabilitation centre. Ninety-five patients diagnosed with COPD (aged 65.0 ± 9.3) with an $FEV_1 < 70\%$ were included and compared with 90 patients diagnosed with CHF (aged 59.6 ± 10.0) with an $LVEF < 45\%$. All patients completed a questionnaire measuring symptoms of dyspnoea, physical functioning, general health perceptions, and personal control.

Results

The results indicate that the relationship between objective health parameters, i.e. FEV_1 or LVEF, and subjective health, i.e. self-reported physical functioning, was not mediated by symptoms of dyspnoea. Both FEV_1 or LVEF and symptoms of dyspnoea were independently related to self-reported physical functioning, which was directly related in turn to general health perceptions. Perceived health competence was related to symptoms of dyspnoea and general health perceptions in patients with either COPD or CHF.

Conclusion

Although patients with COPD reported lower levels in all self-reported health parameters in the model than the patients with CHF, this study showed that the relationships between the health parameters in the model were comparable for COPD patients and CHF patients.

Submitted

Introduction

The development of a chronic illness may lead to a broad range of consequences affecting several aspects of a patient's health[2;3]. These consequences can be regarded as a succession of events or as a set of steps in the illness's progression. This process normally starts at the development of physiological or biological abnormalities, resulting in symptoms and physical limitations that are noticed and reported by the patients. Consequently, these limitations will eventually affect the patients' ability to engage in activities healthy people are usually able to perform. Over time, patients have to face their inability to take part in their usual activities. Accordingly, these physical limitations influence the patients' perceptions of their health and ultimately their general well-being. This chain of consequences of chronic illness runs from the objective effects of the illness (physiological abnormalities), to health status (physical functioning), and ultimately to the subjective perception of health (health perceptions and well-being).

To study the impact of chronic illness, most clinical trials originally used the biomedical model, which assessed the effects of etiological factors on the pathological process and eventually on the biological, physiological, and clinical outcomes[4;5]. The aim of these studies was to enhance diagnosis and treatment of patients and was usually focused on largely objective health indicators. Studies from the social sciences, on the other hand, usually focus on the consequences of disease as perceived by the patients[1;6], and as a result are mainly interested in the subjective consequences of disease. Wilson and Cleary[1] have presented a conceptual model of patient outcomes, a very useful model for studying the sequence from objective to subjective health factors.

Wilson and Cleary's model[1] has contributed substantially to the existing literature on the consequences of disease since it integrates the biomedical model with the social scientific model of health. Wilson and Cleary organise different measures of health from biological factors at one end of the continuum to perceived health at the other end of the continuum. Moreover, this model assumes specific causal relationships between the various health concepts, without reciprocal effects[7]. The five levels in the model, representing different health concepts, are (1) biological and physiological variables, (2) symptom status, (3) functional status, (4) general health perceptions, and (5) overall quality of life (QoL). Only a few previous studies have empirically tested (parts of) Wilson and Cleary's model[7-9], and only one of them tested the sequence from objective to subjective health factors by means of structural equation modelling[7]. This study by Sullivan et al. supported Wilson and Cleary's model to the extent that the relationship between biological variables and general health perceptions was found to be mediated by symptoms and physical functioning. Apart from this indirect effect of biological variables on general health perceptions, Sullivan also reported direct relationships between non-adjacent variables in the model, i.e. between biological variables and physical functioning, between symptoms and general health perceptions, and between physical functioning and general health perceptions[7].

This study investigates Wilson and Cleary's model in patients with Chronic Obstructive Pulmonary Disease (COPD) and patients with Chronic systolic Heart Failure (CHF). Both COPD and CHF are seriously debilitating conditions that have a profound impact on patients' functional status[10] and QoL[11;12]. Furthermore, COPD and CHF are important causes of morbidity and mortality worldwide[13;14]. COPD is characterised by airflow limitation resulting in a reduced ventilatory capacity, and for most patients in shortness of breath or dyspnoea[15]. In many COPD patients, these symptoms of dyspnoea lead to limitations in daily activities. CHF may result from various cardiac disorders and is manifested in symptoms such as dyspnoea and fatigue[16]. The consequences of CHF include a reduced exercise capacity and fluid retention, which may lead to pulmonary and peripheral oedema[14].

The biological or physiological variables from Wilson and Cleary's model were operationalised as pulmonary function for COPD patients, indicated by the forced expiratory volume in one second (FEV_1), an objective measure of airflow limitation[2]. For patients with CHF, objective physical functioning was operationalised as left ventricular function, indicated by the left ventricular ejection fraction (LVEF)[3]. Furthermore, in this study, symptom status in Wilson and Cleary's model was operationalised as dyspnoea, since symptoms of dyspnoea are the main symptoms experienced by both COPD patients and CHF patients.

Some relationships between the health factors in Wilson and Cleary's model remain as yet unclear[1]. In particular, the relationship between biological or physiological variables and symptoms is considered complex. Wilson and Cleary mention that for some disorders, biological or physiological variables are unrelated to symptoms, which may well be the case for the relationship between the FEV_1 and symptoms of respiratory compromise in COPD patients. Other studies have confirmed that FEV_1 and symptoms of dyspnoea were unrelated in COPD patients[17;18]. There is also support for the view that LVEF and symptoms of dyspnoea are unrelated in cardiac patients[19]. Furthermore, previous research has revealed that the level of overall QoL in Wilson and Cleary's model is not completely explained by the other health factors in their model[7]. It is most likely that factors other than health also contribute to patients' perceptions of health and to their well-being. Wilson and Cleary solved this issue by adding external factors to their model, indicated as 'characteristics of the environment' and 'characteristics of the individual', which may affect the health concepts at several levels of the model[1]. One psychological variable possibly related to several aspects of health is personal control. Personal control refers to individuals' beliefs about their ability to exert control over their own lives[20]. Previous research has shown that during the development of a chronic illness a patient's perceptions of personal control are affected[21]. Furthermore, a greater amount of personal control was found to be related to improved well-being[22] and better physical functioning[23].

Various forms of personal control have been described, ranging from the more general to the more specific. This study focused on perceived health competence, which refers to perceived control over personal health[24]. Previous research has revealed a relationship between a higher perceived health competence and more preventive health behaviour like exercise, abstinence from smoking, and weight maintainance[25], and improved physical functioning[26;27]. Consequently, since associations were found between perceived health competence and health-related behaviours and physical functioning, perceived health competence is likely to be related to health at different levels in Wilson and Cleary's model.

Therefore, this study investigated the sequence of outcomes of disease from objective to subjective health in COPD and CHF patients. This study was particularly aimed at two research questions. First, the relationship between objective and subjective health factors was assessed. More specifically, the question of whether the relationships between physiological parameters (forced expiratory volume in 1 second (FEV_1) for COPD and left ventricular ejection fraction (LVEF) for CHF) and general health perceptions was mediated by symptoms of dyspnoea and physical functioning was addressed. In this study, Wilson and Cleary's conceptual model[1] was adapted and tested (Figure 6.1 illustrates the model tested in this study). There may be some support for the proposition that there are relationships between non-adjacent health parameters in the model[7]. Therefore, the relationships between the non-adjacent health parameters in the model were also investigated, particularly between physiological variables and physical functioning, between physiological variables and general health perceptions, and between symptoms of dyspnoea and general health perceptions (see Figure 6.1). In our model, the overall QoL variable was not included, as this variable refers to general well-being and also includes non-medical factors. The second aim of this study was to investigate at which level in the model perceptions of personal control were related to the health parameters for patients with COPD and CHF.

The relationships between the health parameters in the model were tested by means of structural equation modelling and the model was tested on two different patient groups. Although various diseases may have differential effects on health and QoL aspects, the discovery of comparable relationships between the factors in the model for COPD and CHF patients was expected. With respect to clinical characteristics, COPD and CHF are comparable to a certain extent. Both are progressive illnesses[28;29] characterised by dyspnoea and a reduced capacity for exercise[30]. Consequently, although the underlying causes of these disorders are quite different, the processes through which disease affects health for COPD and CHF patients may be comparable.

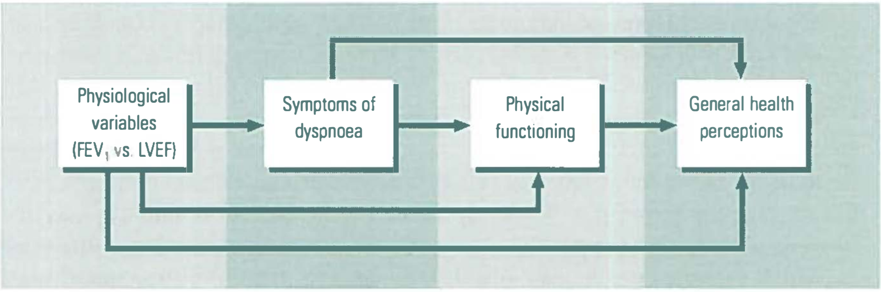

Figure 6.1 Theoretical model, based on Wilson & Cleary[1]

Methods

Patients and study design

Consecutive patients with COPD or CHF were recruited from a university hospital, a general hospital, and a university rehabilitation centre from January 2001 to June 2002. Data from patients in the rehabilitation centre were combined with data from patients in the outpatient clinics for both COPD and CHF. The data used in this study are a part of a larger study that studied the effects of a rehabilitation programme and therefore assessed the COPD and CHF patients both before and after rehabilitation programme participation. The assessment carried out after the patients had finished their rehabilitation programme was used in this study since at that moment the patients were better able to be compared to the patients in the outpatient clinic than before they attended the rehabilitation programme. In this assessment, no significant differences were found between patients from the rehabilitation centre and patients from the outpatient clinics with respect to symptoms of dyspnoea, self-reported physical functioning, and general health perceptions. Furthermore, correlation coefficients between these variables were comparable for patients in rehabilitation and patients from the outpatient clinics for COPD and CHF.

Eligible patients received written information about the study and an informed consent form. COPD patients were included if they were (1) diagnosed with COPD, (2) registered with a forced expiratory volume in 1 second (FEV_1) of less than 70% of the predicted value, and (3) free from other pulmonary disease. Patients with CHF were included if they were (1) diagnosed with CHF, and (2) registered with a left ventricular ejection fraction (LVEF) less than 45%. Furthermore, patients with CHF were excluded if they suffered from angina pectoris or atrium fibrillation, if they had had heart transplant surgery, or if they had recently (in the past year) had a myocardial infarction. Patients in both groups were aged between 40 and 80, free from any other serious disease (such as cancer), free from psychiatric problems over the previous year, and fluent in the Dutch language. The study had a cross-sectional design and data were collected by means of self-report mailed questionnaires. The Medical Ethics Committees of the various centres approved the study.

Assessments

Clinical variables

In the COPD patients group data on lung function parameters (FEV_1 in litres, FEV_1 %pred and FVC in litres) were collected from the patients' medical records. For the CHF patients, information on left ventricular ejection fraction (LVEF) was collected from medical files. Furthermore, the percentages of smokers in both groups and the number of pack-years (number of years patients have smoked x number of cigarettes a day / 20) and illness duration were assessed.

Symptoms of dyspnoea

A short questionnaire measured the number of illness-related symptoms experienced by the patients in the previous week[31]. This questionnaire, originally designed for COPD patients, was adapted for patients with CHF based on the literature[14] and in consultation with cardiologists to incorporate items assessing manifestations of CHF. In this study, items were selected measuring the amount of dyspnoea experienced at rest and during exercise in the previous week, symptomatic of both COPD and CHF. Dyspnoea was measured with two items, ranging from 0 to 6, which were averaged; higher scores indicate that symptoms were more often experienced.

Functional status

The *physical functioning* subscale (10 items) of the Rand 36-item Health Survey[32;33] was selected for the assessment of functional status. Physical functioning measures the extent to which health interferes with daily activities such as climbing stairs. The scores on this subscale vary from 0 to 100; higher scores indicate better functioning.

General health perceptions

The *general health perceptions* subscale (5 items) of the Rand 36-item Health Survey[32;33] measures the perceptions people have concerning their health in general. Again, scores on this subscale vary from 0 to 100 and higher scores indicate better perceived health.

Perceived health competence

The *Perceived Health Competence Scale*[24] measures the degree to which an individual feels capable of effectively managing his or her health outcomes. This scale consists of four positively formulated items and four negatively formulated items. All items add up to a total score (range 8-40) with higher scores indicating greater levels of competence. Examples of items include 'I handle myself well with respect to my health' and 'No matter how hard I try, my health just doesn't turn out the way I would like'.

Socio-demographic variables.

Age, gender, marital status and educational level were assessed. Educational level was assessed according to the International Standard Classification of Education[34;35], which has six categories that were recoded into four categories, ranging from lower to higher educated.

Data analysis

First, t-tests and chi-square tests were performed to compare the COPD and CHF patients with respect to demographic and clinical characteristics. Second, the differences between the groups in symptoms of dyspnoea, physical functioning, general health perceptions and perceived health competence were tested by means of analysis of covariance, to control for age differences between the groups. Third, bi-variate correlation analyses were performed to study the associations of dyspnoea, physical functioning, general health perceptions and perceived health competence in both patient groups.

Fourth, the theoretical model was assessed (see also Figure 6.1) by means of structural equation modelling. Structural equation modelling is a multivariate technique for testing the tenability of a hypothesised model and is an elaboration of regression analysis. In order to be able to perform LISREL, two criteria must be met: first, a causal relationship between two variables is known or assumed on the basis of previous research or theoretical considerations. Second, no reciprocal relationships or 'feedback loops' can be tested. LISREL 8.20 was used to test the hypothesised model. The goodness of fit of the models was judged by three measures. The χ^2 test compares the model to the hypothesised model and should therefore not be significant ($p > 0.05$). The root mean square error of approximation (RMSEA) is an index of model fit, indicated by a value below 0.05. The expected cross validation index (ECVI) is an index taking fit and model parsimony into account, thus prohibiting the addition of too many irrelevant parameters to the model. ECVI values should be low; values lower than the ECVI for the saturated model in particular indicate a good fit for the model[36].

The input for structural equation modelling was the correlation matrix (Table 6.3) with the relationships between FEV_1 or LVEF, dyspnoea, self-reported physical functioning, and general health perceptions. Separate analyses were performed for patients with COPD and CHF in which the same model was tested (illustrated in Figure 6.1). The non-significant paths between the variables were removed one by one to obtain a model with optimal fit and greatest parsimony. Models for both groups were evaluated by examining the parameter estimates and measures of overall fit provided by LISREL.

Fifth, regression analyses were performed to study the relationships between perceived health competence with the various health variables in the model. Three different analyses were performed for each group. First, the extent to which symptoms of dyspnoea could be explained by lung function or ejection fraction and perceived health competence was assessed (after correction for age). In the second analysis, this analysis was repeated with self-reported physical functioning as the dependent variable and as an independent variable in addition to dyspnoea. Third, the same analysis was performed with general health perceptions as the dependent variable and in addition to self-reported physical functioning as an independent variable.

Results

Patient groups

One hundred and thirty-four COPD patients (86 from the outpatient clinic and 48 in rehabilitation) were asked to participate in the study. In the outpatient clinics, of the 86 potential participants, 19 did not respond and 11 refused to participate in the study. In the rehabilitation centre, of the 48 potential participants, 1 patient died, 1 had an exacerbation of COPD, and 7 withdrew from the study before the end of the rehabilitation programme. Patients who were not included in the study did not dif-

Table 6.1 Demographic variables and clinical characteristics of patients with COPD and patients with CHF

	COPD N = 95		CHF N = 90		Difference between groups
	Mean	SD	Mean	SD	p-value
Age (years)	65.0	9.3	59.6	10.0	.001[a]
Gender (% female)	35.8		24.4		n.s.
Educational level (%)					n.s.
Primary	39.0		26.7		
Lower vocational	32.6		35.6		
Secondary/intermediate vocational	15.8		23.3		
Higher vocational/university	12.6		14.4		
Marital status (% with partner)	86.2		81.8		n.s.
FEV$_1$ (litres)	1.39	0.7			
FEV$_1$ (%pred)	45.7	19.0			
FVC (litres)	3.3	0.9			
LVEF (%)			30.3	9.4	
Smoking (%)					n.s.
Smokers	17.9		14.4		
Former smokers	74.7		74.4		
No smokers (never)	7.4		11.2		
Pack-years (years)	35.3	22.2	27.4	22.1	.03[b]
Illness duration (years)	10.2	10.0	6.5	7.9	.01[c]

n.s. = not significant

[a]) differences between groups: t value = 3.8; [b]) t value = 2.2; [c]) t value = 2.5

fer significantly from the participants with respect to age and gender. In total, 95 COPD patients were included in the study (response rate 71%).

In the CHF patient group, 138 patients (110 from the outpatient clinic and 28 in rehabilitation) were invited to the study. Of the 110 potential participants in the outpatient clinic, 45 refused to participate. In the rehabilitation centre, of the 28 potential participants, 3 withdrew from the study before the end of the rehabilitation programme. Patients who were not included did not differ significantly from the participants with respect to gender, but a significant difference was found with respect to age: patients refusing to participate were on average 8 years older than the participants. Ninety CHF patients participated in the study (response rate 65%).

Socio-demographic variables

Table 6.1 shows the demographic and clinical characteristics of the patients with COPD and CHF. The COPD patients were on average 5 years older ($p < 0.001$) than the CHF patients (65.0 and 59.6 years old, respectively). COPD patients reported a significantly higher number of pack-years (35.3) than the CHF patients (27.4). Furthermore, illness duration for COPD patients was on average 3 years longer than for CHF patients (10.2 against 6.5). Other demographic variables did not differ significantly between the groups.

Differences between COPD and CHF in self-reported health and perceived health competence

Table 6.2 shows the unadjusted mean scores with respect to dyspnoea, self-reported physical functioning, general health perceptions, and perceived health competence for both patient groups. The results, after correction for age differences, show that the COPD patients scored significantly worse than the CHF patients on dyspnoea, self-reported physical functioning, general health perceptions, and perceived health competence.

Table 6.2 Self-reported health and perceived health competence of patients with COPD and CHF

	COPD		CHF		Difference between groups
	Mean^a	SD	Mean^a	SD	F-values
Dyspnoea	2.7	1.1	1.8	1.1	28.8*
Physical functioning	38.3	24.7	57.8	26.1	19.9*
General health perceptions	38.4	18.7	49.8	19.9	21.7*
Perceived health competence	24.8	4.5	27.6	4.3	14.2*

^{a}) unadjusted means (uncorrected for age differences between groups)

Analysis of variance between groups: * $p < .001$ (adjusted for age differences)

Relationships between clinical variables, dyspnoea, physical functioning, and general health perceptions

The input for the structural equation modelling consisted of the correlation matrix as presented in Table 6.3 (apart from the correlations for perceived health competence). In both COPD and CFH patients, FEV_1 or LVEF were only significantly related to self-reported physical functioning ($r = 0.22$ for both COPD and CHF). Symptoms of dyspnoea, physical functioning and general health perceptions were significantly interrelated.

Table 6.3 Pearson's correlation coefficients of illness severity (FEV_1 vs. LVEF), dyspnoea, physical functioning (Rand-36), general health perceptions (Rand-36), and perceived health competence for patients with COPD and patients with CHF

		Dyspnoea	Physical functioning	General health perceptions	Perceived health competence
Illness severity					
FEV_1	COPD	.04	$.22^{*}$	.14	.10
LVEF	CHF	-.08	$.22^{*}$	.13	.06
Dyspnoea	COPD		$-.63^{***}$	$-.62^{***}$	$-.41^{***}$
	CHF		$-.69^{***}$	$-.37^{***}$	$-.32^{**}$
Physical functioning	COPD			$.63^{***}$	$.29^{**}$
	CHF			$.52^{***}$	$.40^{***}$
General health perceptions	COPD				$.39^{***}$
	CHF				$.49^{***}$

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

Figures 6.2 and 6.3 show the best fitting models for the patients with COPD and CHF. The parameters for goodness of fit indicate a good fit for the models for COPD and CHF. First, the χ^2 values indicate a good fit ($\chi^2=0.41$, $p=0.81$, $df=2$ for COPD; $\chi^2=0.71$, $p=0.87$, $df=3$ for CHF). Other indices also indicate a good fit. In both COPD patients and CHF patients, the RMSEA value is lower than 0.05 (RMSEA=0.00 for COPD; RMSEA=0.00 for CHF). Furthermore, the ECVI values are lower than the ECVI for the saturated model for the COPD and CFH patients in this study (ECVI=0.18 (sat.=0.22) for COPD; ECVI=0.17 (sat.=0.23) for CHF), which indicates a good fit for both models.

The models show that the FEV_1 variable for COPD patients and LVEF variable for CHF patients were not related significantly to the level of dyspnoea. Nevertheless, FEV_1 and LVEF had a significant effect on self-reported physical functioning ($\beta=0.20$ for COPD; $\beta=0.17$ for CHF). Furthermore, dyspnoea was significantly related to self-reported physical functioning ($\beta=-0.63$ for COPD; $\beta=-0.67$ for CHF) in both groups, whereas physical functioning significantly affected general health perceptions ($\beta=0.39$ for COPD; $\beta=0.52$ for CHF). Only in the COPD patient group was dyspnoea directly related to general health perceptions ($\beta=-0.37$). Therefore, in patients with COPD, general health perceptions were explained by symptoms of dyspnoea and self-reported physical functioning. For patients with CHF, on the other hand, general health perceptions were only explained by self-reported physical functioning.

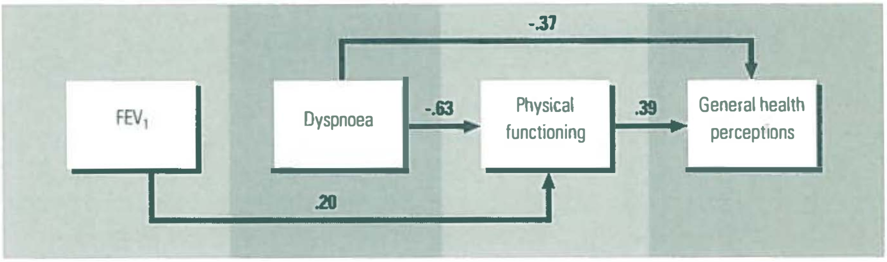

Figure 6.2 Final model of relationships between FEV1, dyspnoea, physical functioning and general health perceptions for patients with COPD

χ^2 = .41 (p = .81; df = 2)
RMSEA = .00
ECVI = .18 (sat. = .22)
N = 93

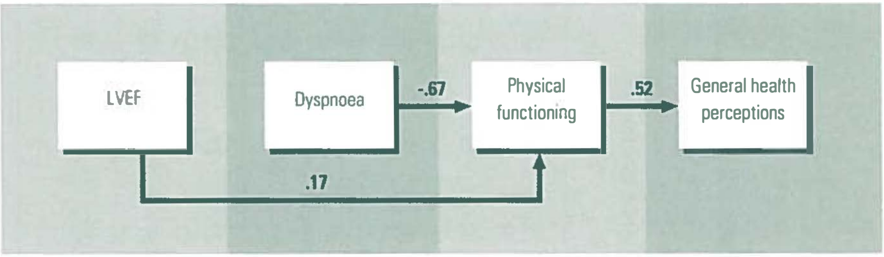

Figure 6.3 Final model of relationships between LVEF, dyspnoea, physical functioning and general health perceptions for patients with CHF

χ^2 = .71 (p = .87; df = 3)
RMSEA = .00
ECVI = .17 (sat. = .23)
N = 88

The results showed that the structural models were nearly identical for COPD and CFH patients. In both patient groups, clinical variables and symptoms of dyspnoea directly affected self-reported physical functioning, which in turn had an effect on general health perceptions. The only difference between both models is that in the COPD patients group, dyspnoea was directly related to general health perceptions.

Relationships between perceived health competence and the variables of health

Three regression analyses were performed for each patient group to study at which level in the model perceived health competence was related to the health parameters. These analyses assessed the extent to which each health parameter in the model was explained by the preceding parameters in the sequence and by perceived health competence. Table 6.4 shows the results of the regression analyses for the COPD and CHF patients.

The results of the regression analyses showed that perceived health competence contributed to the explanation of dyspnoea, although the variables age and FEV$_1$ or LVEF did not contribute to dyspnoea. Only in CHF patients did perceived health

Table 6.4 Regression analysis of general health perceptions (Rand-36) on perceived health competence, illness severity (FEV_1 vs. LVEF), dyspnoea, and physical functioning for patients with COPD (N = 95) and patients with CHF (N = 90)

COPD	**Dyspnoea**				**Physical functioning**				**General health perceptions**			
Predictors	**B**	**SE B**	**β**	**R^2**	**B**	**SE B**	**β**	**R^2**	**B**	**SE B**	**β**	**R^2**
Age	-.01	.01	-.12		-.72	.20	$-.27^{**}$		.51	.16	$.25^{**}$	
FEV_1	.00	.01	.02		.31	.10	$.24^{**}$		-.03	.08	-.03	
Dyspnoea	—	—	—		-14.32	1.79	$-.66^{***}$		-3.49	1.74	$-.21^{*}$	
Physical functioning	—	—	—		—	—	—		.37	.08	$.49^{***}$	
Perceived health competence	-.11	.03	$-.41^{***}$		-.05	.46	-.01		.71	.34	$.17^{*}$	
				.18				**.51**				**.54**

CHF	**Dyspnoea**				**Physical functioning**				**General health perceptions**			
Predictors	**B**	**SE B**	**β**	**R^2**	**B**	**SE B**	**β**	**R^2**	**B**	**SE B**	**β**	**R^2**
Age	.01	.01	.12		-.17	.20	-.07		.65	.16	$.33^{***}$	
LVEF	-.01	.01	-.06		.47	.21	$.17^{*}$		.06	.18	.03	
Dyspnoea	—	—	—		-13.87	1.83	$-.60^{***}$		-.39	1.94	-.02	
Physical functioning	—	—	—		—	—	—		.32	.09	$.42^{***}$	
Perceived health competence	-.08	.03	$-.31^{**}$		1.23	.50	$.19^{*}$		1.61	.42	$.34^{***}$	
				.12				**.54**				**.47**

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

competence contribute to the explanation of physical functioning after the other variables had been entered into the equation. Finally, in both patient groups, perceived health competence contributed significantly to general health perceptions after the variables age, FEV_1 or LVEF, dyspnoea, and physical functioning had been entered into the equation. Therefore, perceived health competence contributed significantly to the explanation of dyspnoea and general health perceptions for both COPD and CHF patients, although perceived health competence was only related to physical functioning in CHF patients.

Discussion

This study investigated the relationship between objective and subjective health factors in patients with COPD and patients with CHF. Consistent with our hypothesis, comparable relationships were found between objective and subjective health parameters for COPD patients and CHF patients. Furthermore, we hypothesised that in addition to the direct effects between the adjacent health parameters in the model (see Figure 6.1), direct associations may also be found between nonadjacent health parameters, such as between physiological variables and physical functioning, and between symptoms of dyspnoea and general health perceptions. The structural models were nearly identical for COPD and CHF patients, which was consistent with our hypothesis. To conclude, the results indicate that the relationship between objective health, i.e. FEV_1 or LVEF, and subjective health, i.e. self-reported physical functioning, is not mediated by symptoms of dyspnoea. On the contrary, FEV_1 or LVEF and symptoms of dyspnoea are independently related to self-reported physical functioning. The relationship of FEV_1 or LVEF and symptoms of dyspnoea to general health perceptions is mediated by self-reported physical functioning for COPD and CFH patients.

Consistent with Wilson and Cleary's model[1], our results have shown that the relationship between objective health, i.e. FEV_1 or LVEF, and general health perceptions is mediated by self-reported physical functioning. Inconsistent with their model, our results did not reveal a relationship between physiological parameters and symptom status. The results we found, though, were consistent with previous studies, which also reported weak correlations between pulmonary or left ventricular function and symptoms of dyspnoea[17-19]. Furthermore, Wilson and Cleary themselves argued that in some disorders, physiological parameters may be unrelated to symptom status[1]. These results indicate that pulmonary or left ventricular function and symptoms of dyspnoea are two different, weakly related aspects of the disorders, although both are related to the physical limitations that patients experience.

The second aim of this study was to investigate at which level in the model perceived health competence was related to health factors. In both COPD and CHF, perceived health competence was related to dyspnoea and general health perceptions once all other health concepts were entered into the equation. Only in CHF patients was perceived health competence significantly related to self-reported physical functioning. Therefore, perceptions of personal control were related to health factors at several levels in the model for both COPD and CHF patients. Perceived health competence in particular was related to symptoms of dyspnoea and general health perceptions in both patient groups.

As the relationships between perceived health competence and several health parameters were cross-sectionally studied, no firm conclusions can been drawn concerning the causality of these relationships. Reciprocal relationships between health parameters and perceptions of competence are very likely to exist[24]. The relationships between symptoms of dyspnoea and perceived health competence and between perceived health competence and general health perceptions found in this study suggest the possibility that perceived health competence is an intervening variable between symptoms of dyspnoea and general health perceptions. It seems plausible that patients who experience more dyspnoea also have a lower level of perceived health competence, which in turn affects their general health perceptions.

A few remarks concerning the methods of this study should be made. Structural equation modelling is a technique testing the tenability of a hypothesised model. Although structural equation modelling produces directional models, it is unable to test causal relationships between the variables when applied to cross-sectional data. Therefore, it cannot be determined whether the different health variables in our model do indeed follow each other chronologically. It would be of interest to study the relationships between these variables longitudinally and, ideally, to include patients from the outset of the development of their illness. Second, in this study, data from patients in the outpatient clinics were combined with data from patients who had just finished their rehabilitation programme. Therefore, as mentioned in the methods section, the possible influence on the results of using data from two different groups was checked and turned out not to be the case. The advantage of including patients in rehabilitation and patients from the outpatient clinics is that the patient samples in this study may better represent the total populations of COPD and CHF patients. Third, the CHF patients who refused to participate were on average eight years older than the participants, indicating selection bias. As a result, the COPD patients were on average five years older than the CHF patients. Therefore, the analyses were corrected for age differences between groups.

This study has both theoretical and clinical implications. Of theoretical importance is the fact that Wilson and Cleary's model of health was empirically tested, something done by only a handful of earlier studies[7-9]. Only Sullivan et al. tested the sequence in health parameters by means of structural equation modelling. This study found direct and indirect effects between the various health parameters in the sequence[7]. Our study contributes to the existing literature, since it provides further insight into the process through which objective and subjective health parameters eventually affect general health perceptions. Moreover, this process was studied in two different patient groups. Only a few recent studies have compared different chronic disorders with respect to health[37-41], yielding inconsistent results, moreover. In this study, important differences were found between both groups with respect to all self-reported health factors in the model. COPD patients reported worse functioning than

CHF patients with respect to dyspnoea, physical functioning, and general health perceptions. Irrespective of these differences between COPD and CHF patients, this study showed that the relationships between the different health factors in the model are largely similar for COPD and CHF patients.

Relevant to clinical practice is the finding that general health perceptions were mainly explained by both self-reported physical functioning and perceived health competence. Apparently, not only physical functioning but also perceptions of personal control are strongly related to patients' perceptions concerning their general health. Furthermore, objective health parameters were not directly related to general health perceptions. This indicates that it is not the physical disorder per se but rather the resultant limitations in physical functioning that are important determinants of the general health perceptions of patients. Though the assessment of pulmonary function or left ventricular function provides an accurate indication of disease severity[2;3], it may be more relevant for a clinician to know the physical limitations patients experience and their perceptions of health competence as these factors are directly related to patients' health perceptions and consequently their well-being[1].

To conclude, this study used Wilson and Cleary's model to assess the relationship between objective and subjective health parameters, and to investigate the relationship between perceived health competence with the health parameters at the various levels in their model. This study contributes to the existing literature by empirically testing Wilson and Cleary's model and by studying this model in two different patient groups, namely patients with COPD and patients with CHF. Although COPD patients evinced lower levels of functioning than the CHF patients in all self-reported health parameters in the model, this study showed that the relationships between the health parameters in the model were largely comparable between COPD and CHF patients. Furthermore, associations were found in both groups between perceived health competence and symptoms of dyspnoea and general health perceptions. In future studies it would be of interest to study Wilson and Cleary's model longitudinally to determine whether the health parameters are indeed causally related and whether perceived health competence is a determinant or rather a consequence of the various health parameters in the model.

Reference List

1 Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA 1995; 273: 59-65.

2 Global Initiative for Chronic Obstructive Lung Disease. Global strategy for the diagnosis, management, and prevention of Chronic Obstructive Pulmonary Disease. NHLBI/WHO workshop report. Update of the management sections. National Heart, Lung and Blood Institute. 2003 Jul 1 [cited 2004 Mar 4] Available from: http://www.goldcopd.com.

3 Hunt SA, Baker DW, Chin MH, Cinquegrani MP, Feldman AM, Francis GS, Ganiats TG, Goldstein S, Gregoratos G, Jessup ML, Noble RJ, Packer M, Silver MA, Stevenson LW. ACC/AHA guidelines for the evaluation and management of chronic heart failure in the

adult: a report of the American College of Cardiology/American Heart Association task force on practice guidelines (committee to revise the 1995 guidelines for the evaluation and management of heart failure). American College of Cardiology Website. 2001. [cited 2004 Mar 5] Available from: http://www.acc.org/clinical/guidelines/failure/hf_index.htm.

4 Stucki G, Sigl T. Assessment of the impact of disease on the individual. Best Pract Res Clin Rheumatol 2003; 17: 451-473.

5 Johnston M, Pollard B. Consequences of disease: testing the WHO international classification of impairments, disabilities and handicaps (ICIDH) model. Soc Sci Med 2001; 53: 1261-1273.

6 Wood-Dauphinee SL. Assessment of back-related quality of life: the continuing challenge. Spine 2001; 26: 857-861.

7 Sullivan MD, Kempen GIJM, Van Sonderen FLP, Ormel J. Models of health-related quality of life in a population of community-dwelling Dutch elderly. Qual Life Res 2000; 9: 801-810.

8 Cosby C, Holzemer WL, Henry SB, Portillo CJ. Hematological complications and quality of life in hospitalized AIDS patients. Aids Patient Care Stds 2000; 14: 269-279.

9 Janz NK, Janevic MR, Dodge JA, Fingerlin TE, Schork MA, Mosca LJ, Clark NM. Factors influencing quality of life in older women with heart disease. Med Care 2001; 39: 588-598.

10 Gosker HR, Lencer NHMK, Franssen FME, Van der Vusse GJ, Wouters EFM, Schols AMW. Striking similarities in systemic factors contributing to decreased exercise capacity in patients with severe chronic heart failure or COPD. Chest 2003; 123: 1416-1424.

11 Ferrer M, Alonso J, Morera J, Marrades RM, Khalaf A, Aguar MC, Plaza V, Prieto L, Anto JM. Chronic obstructive pulmonary disease stage and health-related quality of life. The Quality of Life of Chronic Obstructive Pulmonary Disease Study Group. Ann Intern Med 1997; 127: 1072-1079.

12 Juenger J, Schellberg D, Kraemer S, Haunstetter A, Zugck C, Herzog W, Haass M. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. Heart 2002; 87: 235-241.

13 Pauwels RA, Buist AS, Ma P, Jenkins CR, Hurd SS. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. National Heart, Lung, and Blood Institute and World Health Organization Global Initiative for Chronic Obstructive Lung Disease (GOLD): executive summary. Respir Care 2001; 46: 798-825.

14 Hunt SA, Baker DW, Chin MH, Cinquegrani MP, Feldman AM, Francis GS, Ganiats TG, Goldstein S, Gregoratos G, Jessup ML, Noble RJ, Packer M, Silver MA, Stevenson LW, Gibbons RJ, Antman EM, Alpert JS, Faxon DP, Fuster V, Gregoratos G, et al. ACC/AHA guidelines for the evaluation and management of chronic heart failure in the adult: executive summary. Circulation 2001; 104: 2996-3007.

15 Boueri FMV, Bucher-Bartelson BL, Glenn KA, Make BJ. Quality of life measured with a generic instrument (Short Form-36) improves following pulmonary rehabilitation in patients with COPD. Chest 2001; 119: 77-84.

16 Berry C, McMurray J. A review of quality-of-life evaluations in patients with congestive heart failure. Pharmacoeconomics 1999; 16: 247-271.

17 Wijnhoven HA, Kriegsman DM, Hesselink AE, Penninx BW, de Haan M. Determinants of different dimensions of disease severity in asthma and COPD: pulmonary function and health-related quality of life. Chest 2001; 119: 1034-1042.

18 Singh SJ, Sodergren SC, Hyland ME, Williams J, Morgan MDL. A comparison of three disease-specific and two generic health-status measures to evaluate the outcome of pulmonary rehabilitation in COPD. Respir Med 2001; 95: 71-77.

19 Herlitz J, Wiklund I, Sjoland H, Karlson BW, Karlsson T, Haglid M, Hartford M, Caidahl K. Relief of symptoms and improvement of quality of life five years after coronary artery bypass grafting in relation to preoperative ejection fraction. Qual Life Res 2000; 9: 467-476.

20 Gurin P, Gurin G, Morrison BM. Personal and ideological aspects of internal and external control. Soc Psychol 1978; 41: 275-296.

21 Helgeson VS. Moderators of the relation between perceived control and adjustment to chronic illness. J Pers Soc Psychol 1992; 63: 656-666.

22 Skinner EA. A guide to constructs of control. J Pers Soc Psychol 1996; 71: 549-570.

23 Yates BC, Belknap DC. Predictors of physical functioning after a cardiac event. Heart Lung 1991; 20: 383-390.

24 Smith MS, Wallston K, Smith C. The development and validation of the Perceived Health Competence Scale. Health Educ Res 1995; 10: 51-64.

25 Gebhardt WA, van der Doef MP, Paul LB. The Revised Health Hardiness Inventory (RRHI-24): psychometric properties and relationship with self-reported health and health behavior in two Dutch samples. Health Educ Res 2001; 16: 579-592.

26 Arora N, Johnson P, Gustafson D, McTavish F, Hawkins R, Pingree S. Barriers to information access, perceived health competence, and psychosocial health outcomes: test of a mediation model in a breast cancer sample. Patient Educ Couns 2002; 47: 37-46.

27 Bonetti D, Johnston M, Rodriguez-Marin J, Pastor M, Martin-Aragon M, Doherty E, Sheehan K. Dimensions of perceived control: a factor analysis of three measures and an examination of their relation to activity level and mood in a student and cross-cultural patient sample. Psychol Health 2001; 16: 655-674.

28 Spencer S, Calverley PM, Sherwood-Burge P, Jones PW. Health status deterioration in patients with chronic obstructive pulmonary disease. Am J Respir Crit Care Med 2001; 163: 122-128.

29 Ekman I, Fagerberg B, Lundman B. Health-related quality of life and sense of coherence among elderly patients with severe chronic heart failure in comparison with healthy controls. Heart Lung 2002; 31: 94-101.

30 Hamilton AL, Killian KJ, Summers E, Jones NL. Muscle strength, symptom intensity, and exercise capacity in patients with cardiorespiratory disorders. Am J Respir Crit Care Med 1995; 152: 2021-2031.

31 Van der Molen T, Willemse BMW, Schokker S, Ten Hacken NHT, Postma DS, Juniper EF. Development, validity and responsiveness of the Clinical COPD Questionnaire. Health Qual Life Outcomes [serial online] 2003 Apr 28 [cited 2003 Aug 5];1;[10 screens]. Available from: URL: http://www.hqlo.com/content/1/1/13.

32 Ware JE, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36) : I. Conceptual framework and item selection. Med Care 1992; 30: 473-483.

33 Van der Zee K, Sanderman R, Heyink JW, De Haes HCJM. Psychometric qualities of the RAND 36-item Health Survey 1.0: a multidimensional measure of general health status. Int J Behav Med 1996; 3: 104-122.

34 United Nations Educational Scientific and Cultural Organization. International Standard Classification of Education (ISCED). Paris, France: UNESCO, 1976.

35 Ranchor AV, Bouma J, Sanderman R. Vulnerability and social class: differential patterns of personality and social support over the social class. Pers Indiv Dif 1996; 20: 229-237.

36 Browne MW, Cudeck R. Single sample cross-validation indices for covariance structures. Multivariate Behav Res 1989; 24: 445-455.

37 Sprangers AG, De Regt EB, Andries F, Van Agt HME, Bijl RV, De Boer JB, Foets M, Hoeymans N, Jacobs AE, Kempen GIJM, Miedema HS, Tijhuis MAR, De Haes HCJM. Which chronic conditions are associated with better or poorer quality of life? J Clin Epidemiol 2000; 53: 895-907.

38 Stavem K, Lossius MI, Kvien TK, Guldvog B. The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. Qual Life Res 2000; 9: 865-871.

39 Kempen GIJM, Ormel J, Brilman EI, Relyveld J. Adaptive responses among Dutch elderly: the impact of eight chronic medical conditions on health-related quality of life. Am J Public Health 1997; 87: 38-44.

40 Arnold R, Ranchor AV, Sanderman R, Kempen GIJM, Ormel J, Suurmeijer TPBM. The relative contribution of domains of quality of life to overall quality of life for different chronic diseases. Qual Life Res 2004; 13: 883-896.

41 Schlenk EA, Erlen JA, Dunbar Jacob J, McDowell J, Engberg S, Sereika SM, Rohay JM, Bernier MJ. Health-related quality of life in chronic disorders: a comparison across studies using the MOS SF-36. Qual Life Res 1998; 7: 57-65.

7

General discussion

In the introduction of this thesis, we introduced the concept of adaptation to illness and discussed this process from a theoretical perspective. We discussed that patients who develop a chronic illness have to face many stressors of their illness which relate to symptoms, medical treatment, physical limitations, and in the longer term to restrictions in participation with friends or family in social activities. The development of a chronic illness often leads to psychological stress, which patients must learn to cope with[1]. This process, in which patients learn to deal with the physical, social, and psychological consequences of their disease, can be interpreted as the process of adaptation. However, some patients do not develop strategies for adapting to their illness, and this negatively affects their quality of life (QoL) and well-being[2]. Therefore, it is important to understand the process of adaptation, and to study the factors that are related to more and less successful adaptation. QoL can be interpreted as one of the main outcomes of the process of adaptation.

In the present thesis, we assessed the result of this process of adaptation in terms of QoL, and we investigated the differences in QoL between patients with Chronic Obstructive Pulmonary Disease (COPD) and patients with Chronic Heart Failure (CHF). Furthermore, we investigated the determinants of adaptation by studying the influence of medical and psychological factors on the QoL of patients with COPD and CHF. Personal control has previously been identified as an important factor in the process of adaptation, and therefore, we studied several variables of personal control in relation to QoL.

Different aspects of our research questions were studied in the previous five chapters of this thesis. In the *first part* of this thesis we studied the medical and psychological determinants of adaptation. We compared the QoL of patients with COPD and CHF and studied whether psychological factors – in particular perceptions of personal control – and clinical factors were related to the QoL of these patients. The *second part* of this thesis consists of a rather conceptual study of QoL and its integration within the bio-medical model, and explores the relationships between several components of QoL and health parameters. In this final chapter, our main findings are discussed and conclusions concerning the research questions are presented. In addition, some overall methodological issues regarding the study design and sample are considered. Theoretical implications of this study as well as implications for clinical practice will also be discussed in this chapter. Finally, we will discuss the directions for future research.

Main findings

First part

In *Chapter 2* we focus on patients with COPD and compare those referred for rehabilitation with those who received usual care in the outpatient clinic. We studied whether COPD patients who participated in a rehabilitation programme improved in QoL and perceptions of mastery and self-efficacy. The treatment of patients with COPD can be rather complex, since the efficacy of treatment depends in part on the effort made by each patient to change certain 'unhealthy' behaviours. For example, for pulmonary rehabilitation to be successful it is essential that the patients stop smoking and do more physical exercise. In order to establish progress during rehabilitation, patients need to be motivated to engage in behavioural change. However, patients with COPD are often faced with multiple and complex problems[3], and in many cases are less motivated to change their behaviour, due to previous failed attempts[4]. Moreover, the patients we assessed were seriously ill, according to their lung function parameters[5]. Although pulmonary rehabilitation can offer a good opportunity to integrally treat the multiple limitations of patients with COPD[6], we consider the treatment of COPD patients to be difficult. Previous studies have argued that perceptions of personal efficacy or personal control influence patients' motivation to modify certain behaviours[7]. In addition, these perceptions of personal control have been associated with life style changes, such as physical exercise and smoking cessation[6;8]. Consequently, perceptions of personal control may be related to the effects of pulmonary rehabilitation[9-12]. Moreover, perceptions of personal control may also play an important part in the establishment and the maintenance of the effects of rehabilitation. First, we investigated whether COPD patients, who were referred for pulmonary rehabilitation, changed with respect to QoL and perceptions of personal control during treatment as compared to a reference group of COPD patients in an outpatient clinic, who were not referred. The results of this study showed that COPD patients improved during rehabilitation, with respect to overall QoL and perceptions of self-efficacy, whereas the reference group of COPD patients in the outpatient clinic showed no change on any of the variables measured. Second, we examined whether increased perceptions of mastery and self-efficacy were related to a higher QoL after rehabilitation. Changes in self-efficacy during rehabilitation were related to a better social and psychological functioning after pulmonary rehabilitation. Thus, these results indicate that pulmonary rehabilitation has a positive effect on the self-efficacy of patients with COPD. Since the management of COPD depends on the commitment of patients to engage in several healthy behaviours, strengthening perceptions of self-efficacy in patients with COPD may be very important.

Chapter 3 presents results of patients with either COPD or CHF in outpatient clinic setting. In this chapter we first compared the patients with COPD and CHF with respect to their functioning on domains of QoL, and their perceptions of personal control. The results of this study showed that patients with CHF functioned significantly better than the patients with COPD with respect to physical and psychological functioning and perceived health competence. Second, we investigated whether self-reported physical functioning of patients with COPD and CHF was primarily explained by illness-specific differences related to diagnosis, and whether more generic factors such as illness severity and personal control also contributed to physical functioning. In the first step of regression analysis, both illness-specific factors related to diagnosis, and generic factors such as illness severity and self-efficacy were related to self-reported physical functioning. However, diagnosis and illness severity did not explain additional variance in self-reported physical functioning once the variables of personal control were entered into the analysis. Although differences between groups were found in the extent to which physical functioning was affected, closely related factors such as illness severity and self-efficacy contributed to self-reported physical functioning, with self-efficacy showing the most strong association. Thus, these results suggest that enhancing perceptions of self-efficacy in addition to improving physical functioning, may be important for the treatment of patients with COPD and CHF.

Second part

The results of *Chapter 4* are based on the data from the Groningen Longitudinal Aging Study (GLAS) which investigated the determinants of disease, disability, and well-being in older people. In this chapter we used Spilker's hierarchical QoL model[13;14] in order to study the relationships between domains of QoL and overall QoL in patients with eight different chronic diseases. We also compared these different patient groups with respect to their functioning on domains of QoL and overall QoL. In this study patients without co-morbid conditions who had one of the following eight chronic medical conditions were included along with a group of healthy subjects: lung disorder, heart condition, hypertension, diabetes mellitus, back problems, rheumatoid arthritis, migraine, or dermatological disorders. We compared the groups of chronically ill patients with healthy subjects and results showed that patients with a lung disorder, a heart condition, back problems, rheumatoid arthritis or migraine, reported lower physical and social functioning than the healthy subjects. With respect to psychological functioning and overall QoL, only patients with lung disorders and migraine functioned worse than the healthy subjects. Second, we studied whether physical, social and psychological functioning contributed differentially to overall QoL, and to what extent these domains of QoL together explained overall QoL. The QoL domain psychological functioning contributed to overall QoL for all disorders and for the healthy subjects. Physical functioning contributed to overall QoL only for lung disorders and hypertension. Similarly, social functioning was related to overall QoL only for patients with back problems, rheumatoid arthritis, and migraine. These results indicate that different chronic conditions differentially affect domains of QoL, in particular the psychological domain of QoL, although the overall judgement of QoL in most cases did not differ from healthy subjects. Apparently, domains of QoL and the overall QoL are two alternative interpretations of QoL, since the three domains of QoL could not explain the total amount of variance of overall QoL.

Chapter 5 focuses in further on Spilker's hierarchical model of QoL[13;14] (see also Figure 7.1) and studies the relationships between QoL parameters at all the three levels of the model. This chapter builds on the previous one by adding the third level in Spilker's model, i.e. specific elements of QoL domains, and exploring its relationships with the other levels in the model. To achieve this we focussed on symptoms of dyspnoea as elements of the physical domain of QoL, since these are the predominant symptoms for patients with COPD as well as CHF patients. First, we studied whether symptoms of dyspnoea (level 3) were related to overall QoL (level 1) through the QoL domains physical, social, and psychological functioning (level 2). Symptoms of dyspnoea were both directly and indirectly related to overall QoL through the QoL domains physical and social functioning. Second, we investigated whether the relationship between dyspnoea and overall QoL was similar for patients with COPD and CHF. The results supported a hierarchical sequence of the QoL domains: the relationship between the QoL domain physical functioning and overall QoL was mediated by social functioning for patients with CHD, and mediated by social and psychological functioning for patients with COPD. This implies that, although small differences in the model for COPD and CHF patients were found, in general the direct and indirect relationships between dyspnoea and overall QoL were similar for patients with COPD and patients with CHF. Remarkably, symptoms of dyspnoea directly affected the overall QoL of all patients, indicating the importance of interventions at this level of QoL. Furthermore, although the causes of both illnesses are different, the relationships among symptoms, QoL domains, and overall QoL are comparable in both groups of patients.

In *Chapter 6* we continued to explore the relationship between several health parameters with general health perceptions as the dependent variable. In particular this study investigates the relationship between objective and subjective health parameters in patients with COPD and patients with CHF. In this substudy we tested Wilson and Cleary's conceptual model of patient outcomes[15], which incorporates different aspects of health from biological or physiological factors at one end of the continuum, to QoL at the other (see Figure 7.1). This model integrates both the bio-medical model and the social-scientific model, and consequently shows some overlap with Spilker's model. Figure 7.1 shows the overlapping aspects of the models. We explored the relationship between physiological parameters and general health perceptions, and in particular we assessed whether this relationship was mediated by symptoms of dyspnoea and physical functioning. The results indicate that the relationship between objective health measured by FEV_1 or LVEF, and subjective health in terms of self-reported physical functioning, was not mediated by symptoms of dyspnoea. The relationship between FEV_1 or LVEF and dyspnoea and general health perceptions was mediated by self-reported physical functioning for both groups of patients. The second aim of this study was to investigate at which level in the model perceptions of personal control were related to health parameters for patients with COPD and CHF. For patients with COPD and CHF perceived health competence was related to dyspnoea and general health perceptions. Remarkably, not only physical functioning, but also perceptions of personal control were related to patients' perceptions concerning their health in general. Although patients with COPD reported lower levels of functioning than the CHF patients for all self-reported health parameters in the model, this study showed that the relationships between the parameters in the model were comparable for patients with COPD and CHF.

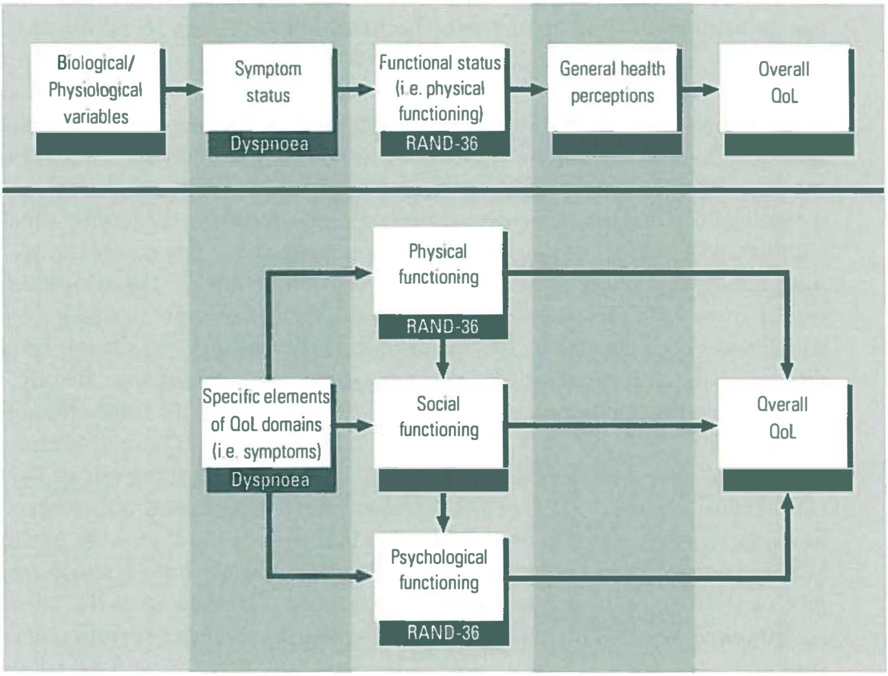

Figure 7.1 Theoretical models of Wilson & Cleary[15] (above) and Spilker[13,14] (below), with operationalisations

Conclusions

In the next section, we will formulate conclusions based on the results of our study with respect to the two following research questions, as formulated in the introduction of this thesis.

Differences in QoL between patients with COPD and CHF

With respect to the outcomes of the process of adaptation of patients, this study showed remarkable differences between patients with COPD and patients with CHF regarding several aspects of their QoL. These differences remain even after we corrected the results for age differences between the groups. Patients with COPD reported a lower physical and psychological functioning than patients with CHF. Furthermore, with respect to symptoms of dyspnoea patients with COPD functioned worse than the CHF patients and they reported worse general health perceptions than the patients with CHF. No significant differences between the groups were found for the social domain of QoL and overall QoL.

Thus, patients with COPD are considerably worse off than patients with CHF regarding many aspects of QoL. However, compared with healthy people of the same age, patients with CHF appear to be limited in physical and social functioning as well[16]. This indicates that patients with COPD as well as patients with CHF are clearly impaired with respect to their QoL, as compared to healthy people. The results of one of our studies based on the Groningen Longitudinal Aging Study, which compared the QoL of eight different chronic disorders, confirmed these findings[17]. Results regarding physical and social functioning showed that patients with most chronic disorders, including heart and lung disorders, differed significantly from the healthy subjects. In contrast, with respect to psychological functioning only a few disorders, including lung disorders, showed worse results than the healthy subjects. Taken together, these results show that differences among disorders exist in the extent to which the QoL of patients has been affected by specific disorders. In particular, the chronic conditions differed in the extent to which the psychological domain of QoL was affected.

Concerning the process of adaptation, we found important similarities between patients with COPD and CHF in the factors that affected their QoL and general health perceptions. For both disorders the relationships between the levels of QoL were comparable: in either COPD or CHF symptoms of dyspnoea and QoL domain social functioning were related to overall QoL. For both groups of patients the relationship between symptoms of dyspnoea and overall QoL was for an important part mediated by QoL domains physical and social functioning. The data from the Groningen Longitudinal Aging Study also showed similarities for patients with different chronic conditions regarding the relationships between QoL domains and overall QoL. In this study the psychological domain was most strongly related to overall QoL. Furthermore, perceptions of self-efficacy were related to self-reported physical functioning for patients with COPD and CHF, and perceived health competence was related to symptoms of dyspnoea and general health perceptions. Thus, although some differences were found between patients with COPD and CHF, the relationships among the different levels of QoL and the relationships between determinants of QoL, in particular variables of personal control, and QoL are comparable.

To conclude, regarding the question whether adaptation to illness is rather a disease-specific or a generic process, we can draw the following conclusions. First, differences between patients with COPD and CHF were found with respect to the outcomes of the process of adaptation, as assessed by QoL measures, which indicates that the level of functioning on several aspects of QoL is different for patients with COPD and CHF. Second, irrespective of these differences between the groups of patients, the underlying mechanisms explaining the QoL of the patients were comparable for patients with COPD and CHF. Consequently, we can conclude that differences exist between chronic disorders in the extent to which QoL has been affected, although generic processes determine the QoL of these patients.

Psychological and medical factors in relation to the QoL of patients with COPD and CHF

In this thesis we showed that perceptions of personal control were to a large extent related to the QoL of the patients with COPD and CHF. First, patients with COPD who participated in a rehabilitation programme improved in perceptions of self-efficacy and these improvements in self-efficacy contributed to social and psychological functioning. Furthermore, perceptions of self-efficacy were related to self-reported physical functioning of both patients with COPD and patients with CHF, even if we accounted for the illness-specific differences related to diagnosis, and illness severity. Second, for COPD as well as CHF perceived health competence was related to symptoms of dyspnoea and general health perceptions. Third, perceptions of mastery were not significantly related to QoL in both groups of patients.

The results indicate that higher levels of personal control, namely self-efficacy and perceived health competence, are related to more favourable outcomes for the patients. Again, this is a generic finding for both COPD and CHF. On the basis of our mostly cross-sectional data, we cannot draw conclusions concerning the causality of these associations, although other studies provide support for the notion that perceptions of personal control indeed lead to positive outcomes for the patients[8-10;18]. In the present thesis, control over health or healthy behaviours appeared to be so important, that it even affected patients' overall perceptions of QoL. Furthermore, perceptions of personal control were related to the outcomes of the process of adaptation as well as to several other variables in the sequence. These findings suggest the importance of personal control in the entire process leading to a better QoL.

In addition, we studied whether clinical factors, in particular lung function parameters or left ventricular function, were related to the different levels of QoL of the patients. First, the results indicate that illness severity was related to self-reported physical functioning for both groups of patients, which implies that patients with worse pulmonary (COPD) or left ventricular (CHF) functions reported a worse physical functioning. Second, with respect to the relationship between objective and subjective health parameters, we found that pulmonary and left ventricular function were not related to symptoms of dyspnoea. Both dyspnoea and pulmonary or left ventricular function were independently related to self-reported physical functioning, which in turn affected general health perceptions. However, pulmonary and left ventricular function were not directly related to general health perceptions.

Thus, objective health parameters such as measures of pulmonary and left ventricular function contributed to limitations in self-reported physical functioning of patients with COPD as well as patients with CHF. However, these measures of objective physical health were not directly related to the general health perceptions of these patients. General health perceptions were only explained by self-reported physical functioning and perceived health competence. Therefore, to predict patients' perceptions concerning their overall health, it is more relevant to know the physical limitations they experience than the severity of the actual underlying pulmonary or cardiac dysfunctions.

With respect to the second research question, we can conclude that medical factors, in particular pulmonary and left ventricular function, as well as perceptions of personal control, affected the process of adaptation in patients with COPD and CHF. Both are related to different aspects of this process of adaptation, though. Pulmonary and left ventricular function were related to physical aspects of functioning, whereas perceptions of personal control were related to both physical and psychosocial aspects of functioning. Consequently, pulmonary and left ventricular function are important determinants of physical limitations, but do not provide insight into how these limitations in turn affect the psychological and social aspects of patients' lives and their overall well-being.

Methodological issues

Despite some methodological flaws, the design of this study also had important advantages. Both issues will be discussed in this paragraph. The main characteristic which discriminates the present study from many previous studies on adaptation is that the QoL of patients with different chronic disorders has been compared and has been related to medical and psychological determinants. In order to understand the process of adaptation, it is important to compare patients with different disorders. The process of adaptation is likely to encompass both specific and generic elements, which can only be revealed by comparing patients with different disorders. Only a limited number of recent studies has compared the QoL of patients with different disorders[19-22]. Consequently, the present study contributes considerably to the existing literature on QoL.

Design of the study

In the present study, we investigated patients with two different chronic diseases, in particular patients with COPD and patients with CHF. In order to assess groups of patients that were as representative as possible of the total populations of patients with COPD and CHF, we recruited patients from different treatment settings. We studied patients with COPD and CHF who were referred to a rehabilitation centre and those who received usual care in the outpatient clinic of a general hospital.

A considerable part of this thesis concerned the study of the relationships between QoL and its clinical and psychological determinants. This thesis also concerned the study of the relationships between several levels of QoL, and the relationships between objective and subjective health parameters. Since we studied the relationships between these variables cross-sectionally, we cannot determine whether these aspects of QoL and health follow one another sequentially, and on the basis of these analyses we cannot assume causal relationships between the variables measured. Moreover, reciprocal relationships between QoL parameters at different levels of specificity, or between objective and subjective health factors are likely, although we were not able to test these relationships. For example, we assumed that symptoms of dyspnoea affect physical functioning, although physical functioning in turn may affect symptoms of dyspnoea. Patients experiencing physical limitations as a result of dyspnoea may refrain from these activities in the future to avoid dyspnoea. However, to abstain from physical activity can lead to a worse physical condition, which in turn leads to more dyspnoea during exercise. Similarly, reciprocal relationships between perceptions of personal control and aspects of QoL and different health parameters may exist.

Ideally, adaptation to illness should be studied from the moment patients first start experiencing the symptoms of their illness or from the moment of diagnosis. Such a design allows to study the process of adaptation longitudinally by investigating the consequences of a chronic illness in their chronological order. Hereby, it is possible to study which domains of QoL are first affected by a disorder and in turn affect other aspects of QoL. Furthermore, such a design supports the study of the relationships between objective and subjective health parameters in a chronological sequence, which implies that the impact of disease indeed develops from physiological parameters and symptoms to physical functioning and general health perceptions (see Figure 7.1). Such a design, though, requires many assessments during the development of the illness.

Although no empirical studies have been found which longitudinally studied the causal relationships among the variables in the models of Spilker and Wilson & Cleary, the theoretical assumptions concerning causality in the models are rather convincing. Spilker's hierarchical model of QoL assumed that QoL assessed at more specific levels affects QoL at a more general level. In particular, the notion that more specific levels of QoL, such as symptoms of dyspnoea and physical functioning, affect overall QoL, is more plausible than vice versa. Patients are likely to base their overall judgement of QoL on their perceptions of physical sensations or actual physical performance, although feedback loops may be possible. Similarly, Wilson & Cleary's model[15] assumes a sequence from specific and objective physiological parameters to more general and subjective perceptions of health. Again, it seems plausible that specific aspects of health affect the more general level of health than vice versa. In any case the process starts with a somatic disorder causing some kind of physiological dysfunction, which in turn results in symptoms or physical limitations. Only in the second place, these physical problems lead to perceptions about these limitations, which may affect social and psychological aspects of functioning, and eventually induces a lower well-being.

One of the studies in this thesis investigated whether COPD patients who participated in a rehabilitation programme improved in perceptions of personal control and QoL. A consequence of our study design in this respect is that we did not randomly assign patients to different treatment settings, and therefore, we cannot draw firm conclusions regarding the effects of the rehabilitation programme. However, our aim was to study changes in QoL and perceptions of personal control during rehabilitation. We did not question whether rehabilitation per se was effective or not, nor did we study the effects of rehabilitation on QoL. Our study of the changes during rehabilitation was part of our more encompassing research question concerning the medical and psychological determinants of QoL. Therefore, our decision for not using a randomised design is of less importance than in studies investigating the effects of a particular treatment, such as a rehabilitation programme.

In general, randomised clinical trials are highly valued methods to test the effects of a particular treatment by administering an intervention to a clearly specified and often homogeneous group of patients and comparing them with similar patients who receive a different treatment. The situation created in randomised clinical trials resembles a relatively controlled experimental setting, which to a certain extent differs from the usual treatment setting. As a result of the well-defined patient samples and treatment settings in randomised trials, patients in these trials are often not representative of the entire population of patients with the particular disorder. Consequently, results found in randomised clinical trials may differ from results gathered in field settings[23]. An advantage of our design is that we did not apply extensive selection criteria for the patients to be included in the study. Therefore, we studied groups of patients which are likely to be rather representative of the patient population of patients with COPD and CHF in medical practice.

Sample characteristics

An important issue concerning the sample described in this thesis is that we consecutively included prevalent patients with COPD and CHF. This way of selecting patients implies that patients were included in different phases of their illness, varying from several months to more than ten years after diagnosis. Consequently, the samples in this study consisted of heterogeneous groups of patients with different medical histories. Due to differences in illness duration, differences in level of adaptation may exist as well. Possibly some patients were adapted to their illness quite well, whereas other patients were still in the beginning of the process of adaptation. Furthermore, crucial events during the progression of the illness, such as an exacerbation or hospitalisation, can also have important consequences for the patients and can lead to differences in adaptation between patients. As a result, considerable differences between patients within the particular disease groups may exist. Nevertheless, this issue is relevant in both groups of patients, since within groups patients varied considerably in illness duration and clinical parameters. Therefore, the issue of heterogeneity within groups probably did not contribute to differences between groups of patients with COPD and patients with CHF. Moreover, we intended to study groups of patients with COPD and CHF that were representative of the total population of patients with these disorders, and therefore we include both incident and prevalent cases in our sample.

An important result of our study was that patients with COPD and CHF differed markedly with respect to the variables of interest in our study as well as with respect to background variables such as age and illness duration. Consequently, selection bias can be an obvious explanation for these results. Since we did not randomly select patients with COPD and CHF, but consecutively included patients according to our criteria of inclusion, it is possible that we included selective subgroups of patients with

COPD and CHF. As a result, the patients with COPD were older than the patients with CHF, which explains the differences in illness duration and, more importantly, explains the fact that patients with COPD reported markedly lower scores on almost all aspects of QoL and personal control than patients with CHF. Although this explanation seems rather plausible, other results do not confirm this hypothesis. First, the results of the Groningen Longitudinal Aging Study (see *Chapter 4*) showed smaller age differences between patients with lung and heart conditions, although still differences were found in the extent to which QoL domains were affected by the disorders. Second, age differences between groups were found both in the outpatient clinic and in the rehabilitation centre, which makes differences due to selection bias rather unlikely. Third, large differences between the groups with respect to QoL and personal control remained, even after correction for age differences between patients with COPD and CHF. Therefore, these differences between groups cannot be explained by age differences alone. Consequently, the differences in QoL and personal control are likely to be disease-specific differences caused by the specific characteristics of the underlying disorders.

An appealing explanation for the age differences between the samples of patients with COPD and CHF is that the populations of patients with COPD treated in outpatient clinic setting or rehabilitation are older than comparable populations of patients with CHF. CHF is a clinical diagnosis which usually results from hypertension or ischemic heart disease, including myocardial infarction. These initial causes of heart failure are frequently acute and life threatening and after patients have recovered from their infarction, they often remain under treatment of a cardiologist in the outpatient clinic. In contrast, the development of COPD progresses rather slowly and many COPD patients are under treatment by their GP's for several years before they are referred to a pulmonologist. Probably, patients with COPD are referred to a specialised physician in later stages of their illness than patients with CHF, which may explain why in the outpatient clinic COPD patients on average are older than patients with CHF.

Our finding that patients with COPD and CHF differed from each other with respect to QoL and perceptions of personal control may be explained by the possibility that patients with COPD were more seriously ill than patients with CHF. Although we compared patients with COPD and CHF with respect to several aspects of QoL, health parameters, and perceptions of personal control, unfortunately it was not possible to compare the objective illness severity of both diseases. Although symptoms of COPD and CHF are to a certain extent comparable, for example symptoms of dyspnoea, the underlying physiological dysfunctions are rather different and therefore, no generic parameter is available to compare the objective illness severity. In one part of our research we tried to solve this issue by using pulmonary and left ventricular function as objective indices of illness severity. In that substudy we compared patients who were severely impaired with patients who were moderately severely impaired regarding their pulmonary or left ventricular function. However, this method does not guarantee that patients with COPD and CHF in the severely impaired group are indeed comparable. Therefore, in other substudies we focused on symptoms of dyspnoea, since these are the main symptoms for patient with COPD as well as for patients with CHF. However, the assessment of dyspnoea consists of the subjective perception of the experience of breathlessness, since dyspnoea cannot be measured objectively. Consequently, the assessment of dyspnoea is determined by the subjective perception of the patients. Moreover, since dyspnoea has different causes for patients with COPD and CHF, we cannot be absolutely sure whether the experience of dyspnoea is similar for patients with COPD and patients with CHF. Nevertheless, in clinical practice it is often hard to distinguish whether the dyspnoea results from pulmonary or cardiac causes. Therefore, we assumed the experience of dyspnoea to be comparable for patients with COPD and patients with CHF. In future research, though, it would be preferable to compare the patients with respect to their actual physical performance, for example by means of a Shuttle Walk Test[24-26], treadmill or bicycle test, to be able to compare the patients with respect to illness severity.

Theoretical implications

Despite the methodological considerations we discussed above, in our research we clearly observed interesting and relevant results, which can be grouped around three different themes. First of all, the study of disease-specific versus generic aspects in adaptation to chronic illness was an important focus of the research described in this thesis. As mentioned before, studying adaptation to illness in different patient groups has the important advantage over studies within one patient group in that disease-specific and generic factors in the process of adaptation can be revealed. A second theme in this thesis was the conceptual study of QoL and its elements. Two specific models of QoL and health parameters were of main importance in our study. Not only did we use these models to describe our results, we also empirically tested these models and studied the relationships among the different variables in these models. Third, the relationships between several variables of personal control and QoL of patients with COPD and CHF occupied an important place in our research. Previous studies have mentioned the important part of perceptions of personal control in the process of adaptation. Therefore, we decided to study different aspects of personal control and to study the differential impact of these factors on the QoL of patients with COPD and CHF. The following part of this general discussion will be organised according to these three central themes in the research of this thesis.

Disease-specific and generic aspects of adaptation

Different diseases can have both disease-specific and generic consequences for the patients involved. Specific for each disease are the clinical manifestations and symptoms caused by the underlying physiological dysfunction. Although many diseases are characterised by different symptoms and limitations, patients with COPD and CHF experience both disease-specific symptoms, such as the production of sputum for COPD and fluid retention for CHF, and generic symptoms, such as dyspnoea. Furthermore, psychological consequences of both diseases are to a certain extent generic: both patients with COPD and patients with CHF have been found to report symptoms of anxiety and depression[27], although the extent to which these patients experience anxiety or depression may differ between patients with COPD and CHF.

One of the main findings of our study is that patients with COPD and patients with CHF differ markedly from each other with respect to their level of functioning on QoL, health and perceptions of personal control. Patients with COPD were more impaired by their illness than patients with CHF. This implies that both physical aspects of functioning, namely symptoms of dyspnoea and self-reported physical functioning, as well as psychological aspects of functioning, such as the psychological domain of QoL, general health perceptions and personal control, were differentially affected by the chronic disorders in this study. Since the underlying physical dysfunctions and causes for both disorders are quite different, it is not surprising that both disorders cause a different extent of physical limitations. However, the result that patients with COPD and CHF also differed from each other in psychological respect, indicates that both disorders may differ in the extent to which they elicit psychological consequences for the patients involved.

To illustrate this idea, we mentioned in the introduction that in many cases CHF is caused by a prior myocardial infarction. A myocardial infarction is an acute cardiac event, which may lead to acute stress and anxiety for the patients. After a while, though, patients discover that they have survived the event. Furthermore, they may even postpone or prevent recurrence of such an event in the future by changing some of their unhealthy behaviours (such as smoking and unhealthy dietary habits). The CHF patients have a different medical background than the patients with COPD. COPD patients have to cope with a disorder which can also largely be attributed to their own behaviour (such as smoking). However, there is little they can do against the progression of the disorder, since this deterioration cannot be stopped, but only be slowed down [28]. Moreover, COPD does not have an acute cause as in many patients with CHF, and therefore, COPD does not elicit acute anxiety or stress, but develops much more chronically. Due to this chronic development, patients with COPD probably experience less acute pressure to change their unhealthy behaviours than patients with CHF. These differences in underlying clinical characteristics may lead to different psychological consequences. For example, the idea that cardiac patients learn about their possibilities to influence their health can explain why patients with CHF reported higher levels of personal control than patients with COPD. In addition, both disorders may have different emotional consequences for the patients. Although anxiety and depression have been found in patients with COPD as well as CHF, depression seems to be the most commonly reported emotional consequence of COPD[29], and more salient than for cardiac patients[27]. Another study showed that patients who had had a myocardial infarction or were diagnosed with CHF reported higher levels of anxiety after diagnosis, whereas just after diagnosis no increase in depressive symptoms was found[30].

Although we did not study which particular characteristics or stressors of the specific disorders explained the differences in QoL between the groups, the results of this study clearly illustrate that different disorders can have a differential psychological impact on the patients. Probably, these differences in psychological impact of disorders are related to the illness perceptions of patients. According to Leventhal's self-regulatory model[31], patients create their own common sense models about their illness, which affect their adaptation to illness. Patients develop perceptions of their illness concerning the symptoms that characterise their illness (identity), the aetiology (causes), the effects and outcomes (consequences), the illness duration (timeline), and the possibilities to control or recover from the illness (controllability/cure)[32].

In contrast to the differences between the disorders in physical and psychological functioning of the patients, we also found generic factors in the process of adaptation. In the second part of this thesis, we tested two models, which studied the interrelations among several levels of QoL and health, in order to study the process of adaptation. First, we found that the relationships between symptoms, domains of QoL, and overall QoL were comparable for patients with COPD and CHF. Second, with respect to the relationship between objective and subjective health parameters, largely the same models were found for patients with COPD and patients with CHF. Consequently, although the level of functioning with respect to QoL and health parameters differs in the separate patient groups, the mechanisms explaining QoL and health are quite comparable for the patients with COPD and CHF. Thus, although COPD and CHF differentially affect the QoL and health of patients, the process of adaptation seems to be generic for patients with COPD and CHF. These results indicate that the models of Spilker and Wilson & Cleary we tested in this thesis apply to patients with different chronic disorders.

Quality of life

The second theme concerned the study of QoL, which is of theoretical importance since it provides thorough insight into the concept of QoL and its elements[14;33]. In the present study, we first studied QoL in depth. In particular, we argued that QoL can be assessed at three levels of specificity (see Figure 7.1). We studied the relationships between aspects of QoL at these three different levels of specificity. Second, we have broadened this study of QoL by focusing at the level of domains of QoL and studying the hierarchy in the relationship between the domains physical, social, and psychological functioning. More specific, we studied whether the relationship between physical functioning and overall QoL was mediated by QoL domains social and psychological functioning. Third, by testing Wilson & Cleary's conceptual model[15], which relates objective and subjective health consequences of disease, we studied QoL integrated with the biomedical model.

Historically, the growing interest in the assessment of QoL has led to an enormous growth in the development of assessment tools to measure QoL[34]. Only much later, the formulation of theories in relation to the concept of QoL started[35]. Consequently, many different definitions, conceptualisations, and models of QoL emerged, and until now a lot of disagreement exists concerning QoL and its assessment[35-37]. In the present study we have tried to organise many of these inconsistencies and we have proposed to solve some of these difficulties by adopting Spilker's QoL model[14]. Moreover, the present study is one of the few that has actually tested this model of QoL and has studied the mechanisms through which a chronic condition affects the QoL of patients.

The results of our study have provided more insight into the way in which illness affects the QoL of the patients at different domains and levels. This study has supported Spilker's model with respect to the assumption that specific physical symptoms indeed affect the general judgement of patients of their QoL and that this relationship was partly mediated by QoL domains physical, social and psychological functioning. Our results have shown that, depending on the kind of chronic illness, QoL may be affected at all three levels of specificity. With respect to the level of specific symptoms (level 3), we found in our study that COPD leads to more symptoms of dyspnoea than CHF. Regarding level 2 of Spilker's model, the results of the comparison of eight different chronic disorders showed that the domains of QoL were differentially affected by different disorders. Many disorders differed from the healthy subjects with respect to physical functioning, whereas only few disorders functioned worse than the healthy subjects with respect to psychological functioning. We found no differences between patients with COPD and CHF with respect to overall QoL (level 1), although the comparison between eight chronic disorders showed that only patients with lung disorders (and patients with migraine) differed in this respect from the healthy subjects.

Previous research argued that a kind of 'gold standard' exists for overall QoL or overall well-being of people in general, across different cultures or nationalities[38]. According to Cummins[39], people intend to maintain a constant level of well-being, regardless of changes in their situation or environment. This tendency of people to maintain a certain level of well-being he referred to as 'homeostasis'. In this respect 'overall QoL or well-being' can easily be confused with a stable personality trait, which did not turn out to be the case. As mentioned above, a few disorders did differ from the healthy subjects with respect to overall QoL, which indicates that these people were not able to maintain their former level of well-being. More plausible is the idea that maintenance of overall well-being can be interpreted as adaptation to illness. When patients have accepted that they no longer have their former level of performance with respect to physical activity or social participation, they will judge their functioning within their current position and no longer will they use their former situation as a frame of reference[40]. This can explain our result that patients with some disorders did not differ from the healthy subjects with respect to overall QoL.

However, does the result that some disorders did differ from the healthy subjects with respect to overall QoL indicate that this group of patients did not adapt to their illness? Cummins argued that only when changes in the situation or environment of people exceed a certain threshold, these factors do affect the subjective well-being of people[41]. This implies that, although most people will eventually adapt to their new situation, some changes are so far-reaching that they exceed the threshold of homeostasis, and therefore make it impossible for them to maintain their former level of well-being or overall QoL. In *Chapter 4* we showed that patients with lung disorders were impaired with respect to all three domains of QoL as well as with respect to their overall QoL. Perhaps due to the impact of the disease on all levels of functioning these patients were no longer able to maintain a 'normal' level of functioning, which resulted in a lower level of overall QoL. Furthermore, patients with COPD as well as patients with CHF reported a lower overall QoL than the 'gold standard' mentioned by Cummins[38]. These results illustrate the serious impact of chronic disorders such as COPD and CHF on the level of well-being of the patients.

Perceptions of personal control

A third important theme in our study was the assessment of several aspects of personal control. In order to study the specific and generic factors in adaptation to illness, we intended to identify the specific characteristics of the different disorders that can lead to different stressors for the patients involved. Previous research has shown that during the development and progression of a chronic illness the perceptions of personal control of the patients are affected[42]. Furthermore, personal control has been associated with adaptation to illness[2], and has been related to a better QoL and well-being[43]. One of our thoughts was that perceptions of personal control can be affected to a greater or lesser extent, depending on the characteristics of specific disorders. For example, we discussed before that CHF is often caused by an acute cardiac event. Although such an event may lead to a lot of anxiety for the patients[27;44], patients can take a few measures, such as to stop smoking and to take medications, to reduce the chance of recurrence of such an event in the future. Patients with COPD have less possibilities to exert control over their symptoms and the progression of their illness and therefore it seems logical that the CHF patients in our study reported higher levels of personal control than the patients with COPD. Thus, differences in clinical characteristics of specific disorders can confront the patients with different problems they have to cope with[45], and consequently differentially affect their perceptions of personal control.

We sought to investigate whether specific aspects of personal control differed with respect to their impact on the adaptation to COPD and CHF. Therefore, we studied different variables of personal control, from global to domain-specific, dependent on the specific research questions, outcome measures, and context of the specific part of the study. Self-efficacy concerns control over specific behaviours necessary to handle an illness[7;46], and has been associated with health promoting behaviours, such as smoking cessation[8] and physical exercise[6]. As a result, we assumed perceptions of self-efficacy to be a relevant factor within the context of rehabilitation and as predictor of physical functioning, which was supported by the results of our study. Mastery and perceived health competence, on the other hand, are more general perceptions of control. Mastery refers to the extent to which people feel they are in control over their lives in general[47]. No differences were found between patients with COPD and CHF with respect to mastery, and neither was mastery related to any of the outcome measures in our study. These results suggest that the consequences of COPD and CHF did not affect the perceptions of the patients regarding their control over their lives in general. The third form of personal control we assessed was perceived health competence, which is the control patients experience over their health[48]. Perceived health competence was related to several aspects of QoL and health for both patients with COPD and CHF. Thus, perceptions of self-efficacy and perceived health competence were found to be important factors related to adaptation of the patients to their illness and were differentially affected by these disorders, since patients with COPD reported lower levels of personal control than patients with CHF.

Clinical implications

Apart from the theoretical implications, this study may also be directive for clinical practice. Once again, we grouped the clinical implications of this study according to the three main themes of this study.

Disease-specific and generic aspects of adaptation

Concerning the disease-specific and generic factors in the process of adaptation an important question related to the treatment of patients with COPD and CHF needs to be addressed. Both disease-specific and generic factors appeared to be important in the process of adaptation to COPD and CHF. Does this imply that the non-pharmacological treatment of patients with COPD can consist of the same elements and can address the same subjects as the non-pharmacological treatment for patients with CHF?

With respect to their level of functioning on aspects of QoL, health, and personal control, we found important differences between the groups of patients with COPD and CHF. Consequently, offering patients with COPD and CHF the same treatment will be rather difficult, when patients with one disorder function markedly worse than the other group. For example, physical exercise training must be tailored to the abilities of specific patients in order to be effective. It seems impossible to design one training programme which is effective for both groups of patients. Furthermore, we argued before that characteristics of specific disorders may confront the patients with disease-specific problems, which lead to different levels of functioning with respect to QoL and health parameters. For example, patients with COPD and CHF both may have to cope with psychological problems, although the content of these problems may be somewhat different. As we mentioned before, patients with cardiac disorders have been found to report higher levels of anxiety, whereas for patients with COPD symptoms of depression may be more relevant. Consequently, the treatment of the patients has to deal with these disease-specific problems and to a certain extent needs to be disease-specific.

Our results have shown that variables at all levels of QoL and health are related to the overall well-being or general health perceptions of the patients. These findings are in favour of an integrated treatment of patients with COPD and CHF in which all levels of functioning are addressed. Such an integrated treatment involves medical professionals with various backgrounds, such as physicians, psychologists, physiotherapists and social workers. Therefore, the integrated treatment of patients with different chronic disorders may be complicated, since all these professionals need to be skilled to treat problems related to different chronic disorders. Consequently, this integrated treatment requires specific focus during the training of physicians on the disease-specific and generic limitations of patients with different chronic conditions.

Apart from the different impairments of patients with COPD and CHF, still these patients are comparable with respect to some clinical characteristics, such as the symptoms they experience. Furthermore, both diseases to a certain extent can be attributed to unhealthy behaviours the patients have engaged in, such as smoking or an inactive lifestyle. The present study shows, that for patients with COPD and CHF the mechanisms through which QoL can be explained were rather similar, that is, similar factors were related to the QoL of the patients. This indicates that at least part of the treatment of patients with COPD and CHF can have the same contents. For example, supporting patients to stop smoking or informing them about how a chronic illness may affect their social and psychological functioning are important elements in the treatment of patients with COPD and patients with CHF. Depending on whether the limitations or problems patients experience are specific for their particular illness or rather inherent in having a chronic disorder in general, parts of their treatment should be disease-specific or generic. For example, the physical training should set different goals for patients with COPD and patients with CHF, since their level of functioning differs remarkably. Furthermore, education concerning the use of medications is an aspect of the treatment, which should be specific for each of the disorders. On the other hand, issues like smoking cessation, maintaining a healthy lifestyle, and returning to work or daily activities are important subjects for both groups and could be discussed in mixed groups of patients with either COPD or CHF. Thus, the treatment of patients with COPD and CHF can be divided in separate parts or modules, some of which are disease-specific, whereas other are applicable for patients with different chronic diseases. Consequently, such a treatment would require both professionals specialised in disease-specific physical limitations, and professionals who are versatilely trained to deal with broad groups of chronically ill patients.

Quality of life

Another important issue with respect to the treatment of patients with COPD and CHF concerns the study of adaptation to illness at three different levels of QoL. At what aspects of QoL and health should the treatment of patients with COPD and CHF be focussed? The results of our study showed that several different factors were related to the overall QoL and general health perceptions of patients with COPD and CHF. Many of these variables were both directly related to QoL and general health perceptions and indirectly, through other health parameters. For example, for both COPD and CHF symptoms of dyspnoea were related to overall QoL through physical and social functioning, but also directly contributed to overall QoL. The result that many different factors directly or indirectly (or both) affected overall QoL and general health perceptions of patients, suggests that an integrated treatment is indicated, which incorporates all levels of functioning that are affected by disease. Ideally, this treatment should aim at all levels of QoL and at all relevant health parameters, namely symptoms of dyspnoea, and physical, social and psychological functioning. Furthermore, part of the treatment should be aimed at improving perceptions of self-efficacy and perceived health competence, since these aspects of personal control were related to several aspects of QoL and health.

Previous research has shown that treatment interventions scarcely affect pulmonary or left ventricular function[49-53]. Therefore, focussing treatment at improving these health parameters is not very useful. Nevertheless, other health parameters, such as dyspnoea and physical functioning are probably more capable of improvement and in addition were also related to the general health perceptions of the patients.

Remarkably, symptoms of dyspnoea were to a large extent directly related to overall QoL for patients with COPD as well as patients with CHF. Not only do these symptoms lead to a lot of physical limitations for the patients, dyspnoea also affects their overall judgement of life in general. This indicates that the impact of these symptoms of dyspnoea on the lives of the patients is so extensive that they affect their overall sense of well-being. Therefore, if possible, an important part of the (medical) treatment of the patients should be aimed at improving symptoms of dyspnoea, by medication or exercise training.

Perceptions of personal control

In the present study, we showed that perceptions of self-efficacy and perceived health competence were related to several aspects of QoL and different health parameters. We argued that on the basis of our results we cannot draw firm conclusions regarding the causality of these relationships. Nevertheless, previous research has shown that people often report lower levels of personal control after they have been confronted with the diagnosis and consequences of a chronic disease[42]. Improving these perceptions of control has been found to be related with higher levels of QoL and well-being. In the previous paragraph, we mentioned that many aspects of QoL and health both directly and indirectly affected the overall QoL and general health perceptions of the patients. Perceptions of self-efficacy and perceived health competence were related to variables at different levels of QoL and to several health parameters. Probably, the relationships between different levels of QoL and health are to a certain extent determined by perceptions of personal control. Thus, also enhancing perceptions of personal control in addition to improving QoL and aspects of health may offer important prospects for the treatment of patients with COPD and CHF. Moreover, improving self-efficacy and perceived health competence may have positive consequences for treatment adherence and the maintenance of the effects of treatment, since perceptions of self-efficacy and perceived health competence have been associated with certain health promoting behaviours. Therefore, paying explicit attention to the improvement of self-efficacy and perceived health competence may lead to improvements in QoL and health parameters, and in addition help to maintain these positive effects.

Future research

We will end this general discussion by formulating some issues that need further attention and which might be interesting to investigate more extensively in future studies.

Disease-specific and generic aspects of adaptation

First of all, in previous paragraphs we argued that our results showed both disease-specific and generic aspects in the process of adaptation to COPD and CHF. Part of the treatment of patients with COPD or CHF needs to be disease-specific and does not apply for both of the disorders. On the other hand, apart from the differences between both disorders, generic factors were found to contribute to the QoL of the patients, which indicates that comparable mechanisms explain the QoL of patients with COPD and CHF.

It would be of interest for future research to study which specific characteristics of the disorders account for the differences in aspects of QoL, health and personal control. In particular it would be important to study in which respects the psychological consequences of both disorders differ from each other, and whether this is related to differences in aspects of QoL. When it has become clear what specific psychological stressors an illness causes, this can provide insight into the subjects that need attention in the treatment of patients with this specific illness. Furthermore, studying the specific psychological consequences of different disorders also provides a better understanding of the comparable consequences of these disorders, and subsequently, of those aspects of the treatments that can be the same for patients with different disorders.

Quality of life

In the present study, we assessed the relationships between three levels of QoL in patients with two chronic disorders. Although the underlying clinical conditions are rather different, these conditions lead to a certain extent to comparable symptoms and limitations. Furthermore, although we found differences between both patient groups in the level of functioning on aspects of QoL, the models for the relationships between aspects of QoL were almost similar in both groups.

We studied these relationships among the levels of QoL cross-sectionally, in prevalent patients who on average had been ill for quite a long time. As a result, the patients in our study had had sufficient opportunity to adapt to their illness to a certain degree. This implies that we rather studied the outcomes of the process of adaptation than the process of adaptation itself. Consequently, in future studies it would be relevant to study the process of adaptation longitudinally and from the moment patients have been diagnosed with their illness, or still more ideally, from the moment they have experienced the first symptoms of their illness. To study the process of adaptation longitudinally, this would also require to longitudinally study the determinants of this process, namely percept ons of personal control and clinical characteristics.

Furthermore, it would be of interest to study whether the relationships among variables at different levels of QoL, we studied in two chronic diseases, are the same for patients who have been diagnosed with illnesses which have a more acute moment of diagnosis and threat of death, such as cancer. Patients with breast cancer, for example, in many cases have not experienced symptoms or physical limitations at diagnosis. In these patients, it is more likely that the psychological domain of QoL has been affected first, before patients start to experience physical or social impairments caused by the illness. Thus, it would be of interest to study the hierarchical QoL model in diseases with a more acute life-threat, such as cancer.

Perceptions of personal control

With respect to perceptions of personal control, we studied their relationships with aspects of QoL and health in two different chronic disorders. An important issue, which needs further attention, is whether in patients with different illnesses other variables of personal control are relevant. In patients with COPD as well as patients with CHF perceptions of self-efficacy were associated with several aspects of QoL, whereas perceived health competence appeared to be related to several health parameters. Thus, in these patients the same variables of personal control were relevant in the explanation of QoL and health. However, both are chronic disorders, which to a certain extent have comparable clinical symptoms and limitations. It would be of interest for future research to study whether this specific variables of personal control are also relevant in the adaptation to other chronic disorders, such as diabetes mellitus, with other clinical symptoms over which more actual control is possible. Moreover, in contrast to our findings, a previous study in cancer patients reported that perceptions of mastery, which is control in general, were more strongly related to the level of distress than disease-specific personal control[54]. Consequently, it should be further investigated whether this finding is specific for this group of cancer patients, or whether the adaptation to more acute life-threatening illnesses indeed involves different forms of personal control.

An important subject, related to the study of perceptions of personal control, is that in general researchers have assumed that perceptions of personal control are beneficial for the patients. However, it may be argued that in cases in which little opportunities exist to control certain aspects of the situation, higher levels of personal control may lead to more stress for individuals. Nevertheless, even in situations in which only little objective control is possible, perceptions of personal control have been found to be related to a better well-being and QoL. For example, cancer is an illness which can be controlled to only a limited extent[55]. Previous studies have shown that even for these patients, who have little possibilities to exert control over their illness or symptoms, perceptions of personal control were beneficial in the process of adaptation to the illness[55-57]. We argued before that patients with COPD and CHF have some possibilities to exert control over their health, for instance to stop smoking or do more physical exercise, although this control is limited since they cannot prevent the progression of their disease. In these patient groups we also found positive associations of personal control perceptions with several aspects of QoL.

Final remarks

In retrospect of this thesis, we may conclude that the results of this research provide more insight into the process of adaptation by studying patients with two different chronic disorders. It is only possible to reveal the disease-specific and generic aspects of this process by comparing patients with different disorders. In particular, the comparison of patients with COPD and CHF made it possible to show the different aspects of functioning between these two patient groups. Furthermore, we showed that different clinical conditions may lead to comparable symptoms, which in turn affect several domains of functioning and the overall level of well-being through similar mechanisms.

An important issue we discussed in the *future research* part of this general discussion concerns the illness-specific stressors that may cause differences between disorders in the extent to which perceptions of personal control, QoL, and different aspects of health have been affected. For the further study of adaptation to illness, it is very important to gain more insight into the processes that lead to differences in psychological consequences between diseases. In the research presented in this thesis, we chose to compare patients with two different chronic disorders to make a thorough study of the disease-specific and generic aspects in the process of adaptation of these patients. In order not to vary too many factors in one study, we compared two patient groups with comparable symptoms and limitations. However, it would be interesting to study patients with other forms of chronic organ failure, such as chronic renal disease or hepatic failure, since these disorders are characterised by other symptoms than those for patients with COPD and CHF. Furthermore, it may be important to study patients with cancer, since this is a disease which at diagnosis confronts the patients with an acute threat of death.

Although still many cancer patients experience the diagnosis of their illness as a 'death sentence', the number of survivors of cancer increases[58], due to better treatment options and medication[59]. Consequently, only recently, cancer has been considered to be a chronic illness[58;60] in stead of 'acute'. Furthermore, the 5-year survival rate for many cancer sites is about 50%[58], which is comparable with the recent 5-year survival rates of CHF[61]. However, still many cancer patients experience their illness as a life-threatening illness[62], whereas for patients with CHF this life-threatening aspect of the disease seems to be less prominent[63]. For patients with COPD survival time is generally much longer, although the overall mortality rates caused by COPD are still very high[64]. Although patients with COPD and CHF probably experience their illness as less acute life-threatening than patients with cancer, their lives are dominated by physical symptoms and impairments. Still much research is needed to study in what ways patients with COPD and CHF can be supported, to offer their lives a higher quality in the years they have left.

Reference List

1 Moos RH, Schaefer JA. The crisis of physical illness. An overview and conceptual approach. In: Moos RH, ed. Coping with physical illness 2: new perspectives. New York: Plenum Medical Book Company, 1984: 3-25.

2 Moos RH, Schaefer JA. Coping resources and processes: current concepts and measures. In: Goldberger L, Breznitz S, eds. Handbook of stress: theoretical and clinical aspects (2nd ed.). New York, NY, Free Press, 1993: 234-257.

3 Lareau SC, ZuWallack R, Carlin B, Celli B, Fahy B, Gosselink R, Jones P, Larson JL, Meek P, Rochester C, Sassi-Dambron D, Stubbing D. Pulmonary rehabilitation-1999. American Thoracic Society. Am J Respir Crit Care Med 1999; 159: 1666-1682.

4 Büchi S, Wolf C, Schwarz F, Villiger B, Buddeberg C. Sind stationäre Rehabilitationsbehandlungen bei Patienten mit chronisch obstruktiver Lungenkrankheit (COLK) sinnvoll? Ergebnisse einer prospektiven 1-Jahres-Verlaufsstudie. Psychother Psychosom Med Psychol 1996; 46: 423-429.

5 Global Initiative for Chronic Obstructive Lung Disease. Global strategy for the diagnosis, management, and prevention of Chronic Obstructive Pulmonary Disease. NHLBI/WHO workshop report. Update of the management sections. National Heart, Lung and Blood Institute. 2003 Jul 1 [cited 2004 Mar 4] Available from: http://www.goldcopd.com.

6 Lox CL, Freehill AJ. Impact of pulmonary rehabilitation on self-efficacy, quality of life, and exercise tolerance. Rehab Psychol 1999; 44: 208-221.

7 Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 1977; 84: 191-215.

8 Meland E, Maeland JG, Laerum E. The importance of self-efficacy in cardiovascular risk factor change. Scand J Public Health 1999; 27: 11-17.

9 Büchi S, Villiger B, Sensky T, Schwarz F, Wolf C, Buddeberg C. Psychosocial predictors of long-term success of in-patient pulmonary rehabilitation of patients with COPD. Eur Respir J 1997; 10: 1272-1277.

10 Lorig KR, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter P, Gonzalez VM, Laurent DD, Holman HR. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care 1999; 37: 5-14.

11 Ketelaars CA, Schlosser MA, Mostert R, Huyer-Abu-Saad H, Halfens RJ, Wouters EF. Determinants of health-related quality of life in patients with chronic obstructive pulmonary disease. Thorax 1996; 51: 39-43.

12 McCathie HCF, Spence SH, Tate RL. Adjustment to chronic obstructive pulmonary disease: the importance of psychological factors. Eur Respir J 2002; 19: 47-53.

13 Spilker B. Introduction to the field of quality of life trials. In: Spilker B, ed. Quality of life assessments in clinical trials. New York: Raven Press, 1990: 3-10.

14 Spilker B, Revicki D. Taxonomy of quality of life. In: Spilker B, ed. Quality of life and pharmacoeconomics in clinical trials. Philadelphia: Lippincott-Raven Publishers, 1996: 25-31.

15 Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA 1995; 273: 59-65.

16 Van der Zee K, Sanderman R, Heyink JW, De Haes HCJM. Psychometric qualities of the RAND 36-item Health Survey 1.0: a multidimensional measure of general health status. Int J Behav Med 1996; 3: 104-122.

17 Arnold R, Ranchor AV, Sanderman R, Kempen GIJM, Ormel J, Suurmeijer TPBM. The relative contribution of domains of quality of life to overall quality of life for different chronic diseases. Qual Life Res 2004; 13: 883-896.

18 Ketelaars CA, Abu-Saad HH, Schlosser MA, Mostert R, Wouters EF. Long-term outcome of pulmonary rehabilitation in patients with COPD. Chest 1997; 363-369.

19 Sprangers AG, De Regt EB, Andries F, Van Agt HME, Bijl RV, De Boer JB, Foets M, Hoeymans N, Jacobs AE, Kempen GIJM, Miedema HS, Tijhuis MAR, De Haes HCJM. Which chronic conditions are associated with better or poorer quality of life? J Clin Epidemiol 2000; 53: 895-907.

20 Stavem K, Lossius MI, Kvien TK, Guldvog B. The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. Qual Life Res 2000; 9: 865-871.

21 Kempen GIJM, Ormel J, Brilman EI, Relyveld J. Adaptive responses among Dutch elderly: the impact of eight chronic medical conditions on health-related quality of life. Am J Public Health 1997; 87: 38-44.

22 Schlenk EA, Erlen JA, Dunbar Jacob J, McDowell J, Engberg S, Sereika SM, Rohay JM, Bernier MJ. Health-related quality of life in chronic disorders: a comparison across studies using the MOS SF-36. Qual Life Res 1998; 7: 57-65.

23 Cook TD, Campbell DT. Quasi-experimentation. Design & analysis issues for field settings. Boston: Houghton Mifflin Company, 1979.

24 Singh SJ, Morgan MD, Scott S, Walters D, Hardman AE. Development of a shuttle walking test of disability in patients with chronic airways obstruction. Thorax 1992; 47: 1019-1024.

25 Singh SJ, Morgan MD, Hardman AE, Rowe C, Bardsley PA. Comparison of oxygen uptake during a conventional treadmill test and the shuttle walking test in chronic airflow limitation. Eur Respir J 1994; 7: 2016-2020.

26 Revill SM, Morgan MD, Singh SJ, Williams J, Hardman AE. The endurance shuttle walk: a new field test for the assessment of endurance capacity in chronic obstructive pulmonary disease. Thorax 1999; 54: 213-222.

27 Lisspers J, Nygren A, Söderman E. Psychological patterns in patients with coronary heart disease, chronic pain and respiratory disorder. Scand J Caring Sci 1998; 12: 25-31.

28 Sutherland ER, Allmers H, Ayas NT, Venn AJ, Martin RJ. Inhaled corticosteroids reduce the progression of airflow limitation in chronic obstructive pulmonary disease: a meta-analysis. Thorax 2003; 58: 937-941.

29 McSweeny AJ, Labuhn KT. Chronic Obstructive Pulmonary Disease. In: Spilker B, ed. Quality of Life assessment in clinical trials. New York: Raven Press, 1990: 391-417.

30 Van Jaarsveld CHM, Sanderman R, Miedema I, Ranchor AV, Kempen GIJM. Changes in health-related quality of life in older patients with acute myocardial infarction or congestive heart failure: a prospective study. J Am Geriatr Soc 2001; 49: 1052-1058.

31 Leventhal H, Nerenz D, Steele DJ. Illness representations and coping with health threats. In: Baum A, Taylor SE, singer JE, eds. Handbook of Psychology and Health. Hillsdale: Lawrence Erlbaum Associates, 1984: 219-252.

32 Weinman J, Petrie KJ, Moss-Morris R, Horne R. The Illness Perception Questionnaire: a new method for assessing the cognitive representation of illness. Psychol Health 1996; 11: 431-445.

33 Fries JF, Singh G. The hierarchy of patient outcomes. In: Spilker B, ed. Quality of life and pharmacoeconomics in clinical trials. Philadelphia: Lippincott-Raven Publishers, 1996: 33-40.

34 Wood-Dauphinee SL. Assessment of back-related quality of life: the continuing challenge. Spine 2001; 26: 857-861.
35 Taillefer MC, Dupuis G, Roberge MA, Le May S. Health-related quality of life models: systematic review of the literature. Soc Indic Res 2003; 64: 293-323.
36 Rogerson RJ. Environmental and health-related quality of life: conceptual and methodological similarities. Soc Sci Med 1995; 41: 1373-1382.
37 Hunt SM. The problem of quality of life [editorial]. Qual Life Res 1997; 6: 205-212.
38 Cummins RA. On the trail of the gold standard for subjective well-being. Soc Indic Res 1995; 35: 179-200.
39 Cummins RA. The second approximation to an international standard for life satisfaction. Soc Indic Res 1998; 43: 307-334.
40 Sprangers MAG, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. Soc Sci Med 1999; 48: 1507-1515.
41 Cummins RA. Objective and subjective quality of life: an interactive model. Soc Indic Res 2000; 52: 55-72.
42 Helgeson VS. Moderators of the relation between perceived control and adjustment to chronic illness. J Pers Soc Psychol 1992; 63: 656-666.
43 Skinner EA. A guide to constructs of control. J Pers Soc Psychol 1996; 71: 549-570.
44 Alonzo AA, Reynolds NR. The structure of emotions during acute myocardial infarction: a model of coping. Soc Sci Med 1998; 46: 1099-1110.
45 De Ridder D, Schreurs KMG, Bensing JM. Adaptive tasks, coping and quality of life of chronically ill patients: the cases of Parkinson's disease and chronic fatigue syndrome. J Health Psychol 1998; 3: 87-101.
46 Carver CS, Harris SD, Lehman JM, Durel LA, Antoni MH, Spencer SM, Pozo-Kaderman C. How important is the perception of personal control? Studies of early stage breast cancer patients. Pers Soc Psychol Bull 2000; 26: 139-149.
47 Pearlin LI, Lieberman MA, Menaghan EG, Mullan JT. The stress process. J Health Soc Behav 1981; 22: 337-356.
48 Smith MS, Wallston K, Smith C. The development and validation of the Perceived Health Competence Scale. Health Educ Res 1995; 10: 51-64.
49 Goldstein RS, Gort EH, Stubbing D, Avendano MA, Guyatt GH. Randomised controlled trial of respiratory rehabilitation. Lancet 1994; 344: 1394-1397.
50 Ries AL, Kaplan RM, Limberg TM, Prewitt LM. Effects of pulmonary rehabilitation on physiologic and psychosocial outcomes in patients with chronic obstructive pulmonary disease. Ann Intern Med 1995; 122: 823-832.
51 Hui KP, Hewitt AB. A simple pulmonary rehabilitation program improves health outcomes and reduces hospital utilization in patients with COPD. Chest 2003; 124: 94-97.
52 Willenheimer R, Erhardt L, Cline C, Rydberg E, Israelsson B. Exercise training in heart failure improves quality of life and exercise capacity. Eur Heart J 1998; 19: 774-781.
53 Pina IL, Apstein CS, Balady GJ, Belardinelli R, Chaitman BR, Duscha BD, Fletcher BJ, Fleg JL, Myers JN, Sullivan MJ. Exercise and heart failure: a statement from the American Heart Association Committee on exercise, rehabilitation, and prevention. Circulation 2003; 107: 1210-1225.

54 Ranchor AV, Arnold R, Schroevers MJ, Stiegelis HE, Ormel J, Sanderman R. Algemene controle versus ziektespecifieke controle in relatie tot aanpassing aan kanker. Gedrag Gezondh 2002; 30: 167-177.
55 Thompson SC, Sobolew-Shubin A, Galbraith ME, Schwankovsky L, Cruzen D. Maintaining perceptions of control : finding perceived control in low-control circumstances. J Personal Soc Psychol 1993; 64: 293-304.
56 Taylor SE, Lichtman RR, Wood JV. Attributions, beliefs about control, and adjustment to breast cancer. J Personal Soc Psychol 1984; 46: 489-502.
57 Terry DJ, Hynes GJ. Adjustment to a low-control situation: reexamining the role of coping responses. J Pers Soc Psychol 1998; 74: 1078-1092.
58 Gerber LH. Cancer rehabilitation into the future. Cancer 2001; 92: 975-979.
59 Bauld C, Anderson V, Arnold J. Psychosocial aspects of adolescent cancer survival. J Paediatr Child Health 1998; 34: 120-126.
60 Hughes MK. Sexuality and the cancer survivor: a silent coexistence. Cancer Nurs 2000; 23: 477-482.
61 Levy D, Kenchaiah S, Larson MG, Benjamin EJ, Kupka MJ, Ho KK, Murabito JM, Vasan RS. Long-term trends in the incidence of and survival with heart failure. N Engl J Med 2002; 347: 1397-1402.
62 Petrie KJ, Buick DL, Weinman J, Booth RJ. Positive effects of illness reported by myocardial infarction and breast cancer patients. J Psychosom Res 1999; 47: 537-543.
63 Ekman I, Ehnfors M, Norberg A. The meaning of living with severe chronic heart failure as narrated by elderly people. Scand J Caring Sci 2000; 14: 130-136.
64 Boezen HM, Postma DS, Smit HA, Gijsen R, Poos MJJC. Hoe vaak komen astma en COPD voor en hoeveel mensen sterven eraan? RIVM. Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. 2003 Sep 15 [cited 2004 Mar 3] Available from: http://www.nationaalkompas.nl.

Summary

From the onset of their illness, patients with a chronic condition have to deal with many consequences of their illness, such as symptoms, physical limitation, restrictions in social activities and psychological problems. This process in which patients learn to cope with these limitations is often interpreted as a process of adaptation to illness. This thesis studies this process of adaptation in patients with Chronic Obstructive Pulmonary Disease (COPD) and patients with Chronic Heart Failure (CHF) and investigates whether these patients differ from each other with respect to adaptation to their illness in terms of quality of life (QoL). We chose to study patients with these two disorders, since both are highly prevalent, chronic disorders. Furthermore, the clinical characteristics of both disorders are to a certain extent comparable. First, we studied the differences in QoL between patients with COPD and patients with CHF. Second, we investigated the determinants of adaptation by studying the relationship between medical and psychological factors and QoL of patients with COPD and patients with CHF.

Chronic Obstructive Pulmonary Disease (COPD) is the result of different disease processes and is characterised by airflow limitation, which is not fully reversible by pharmacological treatment. The diagnosis of COPD includes patients with chronic bronchitis and pulmonary emphysema. Most patients with COPD experience symptoms such as chronic cough, dyspnoea, production of sputum, and wheeze. The lung function of COPD patients continually deteriorates and consequently, patients with COPD experience a gradual deterioration in functional status. Smoking is the most important contributing factor in the development of COPD. COPD is one of the most prevalent medical conditions and is the fourth leading cause of death worldwide. Further increase of the prevalence and mortality caused by COPD are expected.

Successful treatment of patients with a myocardial infarction has resulted in an increasing number of patients with Chronic Heart Failure (CHF). Heart failure is a complex clinical syndrome, which is the result of different disease processes that lead to a reduced cardiac function, caused by the ventricle's failure to sufficiently fill with or eject blood. Manifestations of heart failure are dyspnoea and fatigue, which may lead to a reduced exercise capacity, and fluid retention, which may cause pulmonary congestion and peripheral oedema. In the present thesis, we focused on left ventricular systolic heart failure. This left ventricular dysfunction is a progressive process. The most important causes of heart failure are hypertension or coronary heart disease. Risk factors for heart failure are increasing age, diabetes, cigarette smoking and obesity. Heart failure has been acknowledged to be a common and growing public health problem. It is a serious disease with a bad prognosis, which reduces the life-span of patients dramatically.

To assess psychological adaptation to COPD and CHF for a wide range of patients, we recruited patients in different treatment settings. In the first place, we recruited patients with COPD and CHF who had been referred for a rehabilitation centre. Second, prevalent patients with COPD and CHF who received usual care in an outpatient clinic setting were included in this study. The study described in the present thesis consisted of two assessments. Patients with COPD or CHF in rehabilitation were evaluated both before and after they participated in the rehabilitation programme. Patients with COPD and CHF in the outpatient clinics were assessed at an interval of four months. Consecutive patients were recruited from January 2001 to June 2002.

The present thesis has been divided in two different parts. In the first part of this thesis, we explored the relationship between several aspects of personal control and QoL in patients with COPD and CHF. Several forms of personal control can be discriminated, including mastery, perceived health competence, and self-efficacy. Mastery is the extent to which people feel in control of the forces that affect their lives. Perceived health competence is a more specific form of personal control that refers to control over one's health. A third form of personal control is self-efficacy, which concerns people's subjective estimation of their capacity for engaging behaviours to control their illness. The second part of this thesis concerns the more theoretical study of the concept of QoL, health, and the different underlying aspects of health. *Chapter 7* presents a summary and general discussion of the main results and implications of these findings.

First part

In *Chapter 2* we focus on patients with COPD and compare those referred for rehabilitation with those who received usual care in the outpatient clinic. We studied whether COPD patients who participated in a rehabilitation programme improved in perceptions of mastery and self-efficacy and whether these perceptions of personal control were related to better outcomes of pulmonary rehabilitation in patients with COPD. The efficacy of treatment of patients with COPD depends in part on the effort made by each patient to change certain 'unhealthy' habits. For example, for pulmonary rehabilitation to be successful, it is essential that the patients stop smoking and do more physical exercise. Smoking is the most important contributing factor in the development and progression of COPD, that many patients find hard to change. In order to establish progress during rehabilitation, patients need to be motivated to engage in behavioural change. However, patients with COPD are often faced with multiple and complex problems, and in many cases are less motivated to change their behaviour, due to previous failed attempts. Failed efforts to change their unhealthy behaviour may result in decreases in their perceptions of control. Moreover, the patients we assessed were seriously ill according to their lung function parameters. Although pulmonary rehabilitation can offer a good opportunity to integrally treat the multiple limitations of patients with COPD, the treatment of COPD patients is not always successful. Previous studies have argued that perceptions of personal efficacy or personal control influence patients' motivation to modify certain behaviours. In addition, these perceptions of personal control have been associated with life style changes, such as physical exercise and stopping smoking. Consequently, perceptions of personal control may be related to the effects of pulmonary rehabilitation. Moreover, perceptions of personal control may also play an important part in the establishment and the maintenance of the effects of rehabilitation. Therefore, we first studied whether COPD patients who were referred for rehabilitation, changed with respect to QoL and perceptions of personal control during treatment as compared to a reference group of COPD patients in an outpatient clinic who were not referred for rehabilitation. The results of this study showed that COPD patients improved during rehabilitation with respect to overall QoL and perceptions of self-efficacy, whereas the reference group of COPD patients in the outpatient clinic showed no change on any of the variables measured. Second, we examined whether increased perceptions of mastery and self-efficacy were related to a higher QoL after rehabilitation. Changes in self-efficacy during rehabilitation in self-efficacy were related to a better social and psychological functioning after pulmonary rehabilitation. Thus, these results indicate that pulmonary rehabilitation has a positive effect on the self-efficacy of patients with COPD. Since the management of COPD depends on the commitment of patients to engage in healthy behaviour, strengthening perceptions of self-efficacy in patients with COPD may be very important.

Chapter 3 presents the results of patients with either COPD or CHF in the outpatient clinics. With respect to clinical characteristics, COPD and CHF are rather comparable: both are progressive diseases, characterised by breathlessness and a diminished exercise capacity. Although patients with COPD and CHF experience comparable limitations, differences between the diseases may exist in the extent to which QoL domains have been affected, since for both COPD and CHF the underlying causes of the functional limitations are quite different. However, the factors that contribute to QoL in COPD and CHF may be comparable, that is, the processes through which QoL of patients with COPD and CHF is affected, may be comparable. Therefore, we first compared patients with COPD and CHF with respect to QoL domains and their perceptions of personal control. The results of this study showed that patients with CHF functioned significantly better than the patients with COPD with respect to physical and psychological functioning and perceived health competence. Second, we studied whether self-reported physical functioning of patients with COPD and CHF was primarily explained by illness-specific differences related to diagnosis, and whether more generic factors such as illness severity and perceptions of personal control also contributed to physical functioning. In the first step of the regression analysis, both illness-specific factors related to differences in diagnosis, and a generic factor, namely illness severity, were related to self-reported physical functioning. However, diagnosis and illness severity did not explain additional variance of self-reported physical functioning once the variables of personal control were entered into the analysis. Although differences between groups were found in the extent to which physical functioning was affected, generic factors such as illness severity and self-efficacy contributed to self-reported physical functioning, with self-efficacy showing the strongest association. Thus, these results suggest that enhancing perceptions of self-efficacy in addition to improving physical functioning may be important for the treatment of patients with COPD and CHF.

Second part

The results of *Chapter 4* are based on the data from the Groningen Longitudinal Aging Study (GLAS), which investigated the determinants of disease, disability, and well-being in older people. This chapter focuses on the relationship between domains of QoL and overall QoL in patients with eight different chronic diseases. Despite the growing interest of clinical and social scientific studies in the assessment of QoL of chronically ill patients, no uniform definition of QoL exists. In this chapter, we use Spilker's hierarchical model of QoL in order to study the relationships between domains of QoL and overall QoL in patients with eight different chronic diseases. We also compare these different patient groups with respect to their functioning on domains of QoL and overall QoL. As a result of disease-specific factors, such as specific symptoms or limitations, different medical conditions may have a differential impact on the domains of QoL of the patients, and, consequently, the relationship between domains of QoL and overall QoL may vary across disorders. Therefore, we studied this relationship between domains of QoL and overall QoL in different disease groups. In this study, we selected patients with one of the following eight chronic medical conditions, without co-morbid conditions: lung disorder, heart condition, hypertension, diabetes mellitus, back problems, rheumatoid arthritis, migraine, or dermatological disorders. We compared the groups of chronically ill patients with a group of healthy subjects and the results showed that patients with a lung disorder, a heart condition, back problems, rheumatoid arthritis or migraine reported lower physical and social functioning than healthy subjects. With respect to psychological functioning and overall QoL, only patients with lung disorders and migraine functioned worse than the healthy subjects. Second, we studied whether physical, social and psychological functioning contributed differentially to overall QoL and to what extent these domains of QoL together explained overall QoL. Psychological functioning contributed to overall QoL for all disorders and for the healthy subjects, whereas physical functioning contributed to overall QoL only for lung disorders and hypertension. Similarly, social functioning was related to overall QoL only for patients with back problems, rheumatoid arthritis, and migraine. These results indicate that different chronic conditions differentially affect domains of QoL, in particular the psychological domain of QoL, although the overall judgement of QoL in most cases did not differ from healthy subjects. Apparently, domains of QoL and overall QoL are two different ways to interpret QoL, since the three domains of QoL did not explain the total amount of variance of overall QoL.

Chapter 5 focuses in further on Spilker's hierarchical model of QoL and studied the relationships between QoL parameters at all three levels of the model. This chapter builds on the previous one by adding the third level in Spilker's model, i.e. specific elements of QoL domains, and exploring its relationships with the other levels in the model. This implies that we studied QoL at the overall level of life quality, at the level of the domains physical, social, and psychological functioning, and at the level of the underlying aspects of QoL domains. We chose symptoms of dyspnoea to represent the third level of Spilker's model as elements of the physical domain of QoL, since these are the predominant symptoms for patients with COPD as well as CHF patients. Moreover, we tested Spilker's model by means of structural equation modelling. First, we studied whether symptoms of dyspnoea (level 3) were related to overall QoL (level 1) through the QoL domains physical, social, and psychological functioning (level 2). Symptoms of dyspnoea were both directly and indirectly related to overall QoL through QoL domains physical and social functioning. Second, we studied whether the relationship between dyspnoea and overall QoL was similar for patients with COPD and patients with CHF. Furthermore, we hypothesised a hierarchical ordering among the QoL domains at level 2 of Spilker's model, that is, we hypothesised that the physical domain of QoL affected overall QoL through the domains social and psychological functioning. The results supported a hierarchical sequence of the QoL domains: the relationship between physical functioning and overall QoL was mediated by social functioning for patients with CHF, and mediated by social and psychological functioning for patients with COPD. This implies that, although small differences in the model for COPD and CHF patients were found, in general the direct and indirect relationships between dyspnoea and overall QoL were similar for patients with COPD and patients with CHF. Remarkably, symptoms of dyspnoea directly affected the overall QoL of the patients, indicating the importance of interventions at this level of QoL. Furthermore, although the causes of both illnesses are different, the relationships among symptoms, QoL domains, and overall QoL are comparable in both groups of patients.

In *Chapter 6* we continue to explore the relationships between several health parameters and general health perceptions as the dependent variable. In particular this study investigated the relationship between objective and subjective health parameters in patients with COPD and patients with CHF. We tested Wilson and Cleary's conceptual model of patient outcomes, which incorporates different aspects of health from biological or physiological factors at one end of the continuum to QoL at the other. We chose to study this model, since it incorporates both objective physical health indicators and more subjective health factors, such as perceived health and overall QoL. Thus, this model integrates both the biomedical model used in clinical studies and the social scientific model adapted in psychological studies, and consequently shows some overlap with Spilker's model. The aim of this study was to investigate the relationship between objective and subjective health parameters in patients with COPD and in patients with CHF. In particular, we studied whether the relationship between objective health parameters (pulmonary function for COPD and left ventricular function for CHF) and general health perceptions was mediated by symptoms of dyspnoea and physical functioning. The results indicate that the relationship between objective health measured by pulmonary or left ventricular function, and subjective health in terms of self-reported physical functioning was not mediated by symptoms of dyspnoea. The relationship between pulmonary or left ventricular function and dyspnoea and general health perceptions was mediated by self-reported physical functioning for both groups of patients. The second aim of this study was to investigate at which level in the model perceptions of personal control were related to the health parameters for patients with COPD and CHF. For both patients with COPD and patients with CHF, perceived health competence was related to dyspnoea and general health perceptions. Remarkably, not only physical functioning, but also perceptions of personal control were related to patients' perceptions concerning their health in general. Although patients with COPD reported lower levels of functioning than the CHF patients for all self-reported health parameters in the model, this study showed that the relationships between the parameters in the model were comparable for patients with COPD and CHF. Although the underlying causes of COPD and CHF are quite different, the processes through which the different aspects of health affect each other appeared to be comparable for patients with COPD and CHF.

Chapter 7 presents a summary of the main findings of this thesis and general discussion of the implications of these findings. The development of a chronic illness often leads to psychological stress, which the patients have to cope with. However, not all patients do develop strategies to adapt to their illness, which negatively affects their QoL and well-being. Therefore, it is important to gain more insight into this process of adaptation, and the factors related to adaptation. QoL can be interpreted as one of the main outcomes of this process of adaptation. In this thesis, we assessed the QoL of patients with COPD and CHF in order to study their adaptation to illness. The first research question addressed the differences between patients with COPD and CHF with respect to adaptation to illness, in terms of QoL. The results of this thesis showed differences between patients with COPD and CHF with respect to the outcomes of the process of adaptation, as assessed by QoL measures, which indicates that the level of functioning on several aspects of QoL is different for patients with COPD and CHF. Irrespective of these differences between the groups of patients, the underlying mechanisms explaining the QoL of the patients were comparable for patients with COPD and CHF. Differences exist between chronic disorders in the extent to which their QoL has been affected, although generic processes lead to the level of functioning on QoL of the patients. The second research question of this thesis concerned the medical and psychological factors related to adaptation to illness. With respect to this second question, we concluded that both medical factors, i.e. pulmonary and left ventricular function, and perceptions of personal control affected the process of adaptation in patients with COPD and CHF. Both are related to different aspects of this process of adaptation, though. Pulmonary and left ventricular function were related to physical aspects of functioning, whereas perceptions of personal control were both related to the physical and psychosocial aspects of functioning. Pulmonary and left ventricular function are important determinants of physical limitation, but do not provide insight into how these limitations in turn affect the psychological and social aspects of patients' lives and their overall well-being.

In addition to these main conclusions, *Chapter 7* addresses a few methodological issues regarding the design of the study and the sample characteristics. Furthermore, theoretical as well as clinical implications are mentioned. These implications are grouped around three central themes. First of all, the study of disease-specific versus generic aspects in the process of adaptation to illness was of main importance in the research described in this thesis. Both disease-specific and generic factors in the process of adaptation to illness were found. Consequently we argued that the treatment of patients with COPD and CHF can consist of both disease-specific and generic elements. Future studies may focus on the specific characteristics of disorders that account for the differences in aspects of QoL in order to reveal which aspects of the treatment can be performed equally for both disorders. Second, the conceptual study of QoL and its elements was an important focus in the present thesis. Two specific models of QoL and health parameters were described and studied, and formed the basis of a part of this thesis. The results of this thesis have provided more insight into the effects of disease on several levels of QoL and the relationships between these aspects of QoL. An integrated treatment was suggested, which aims at functioning of the patients at all three levels of QoL. In future studies, it would be relevant to study the relationships between the levels of QoL longitudinally, from the moment the patients have experienced the first symptoms of their illness. A third theme in this thesis was the study of personal control and the relationships between several aspects of personal control and QoL, since personal control has been found to be an important determinant of QoL and well-being of chronically ill patients. Perceptions of self-efficacy and perceived health competence were found to be important factors in the process of adaptation to COPD and CHF. A more explicit focus on perceptions of personal control in the treatment of patients with COPD and CHF may lead to improvements in QoL. It would be of interest to further study whether these specific variables of personal control are also relevant in the adaptation to other diseases.

Samenvatting

Vanaf het moment dat bij patiënten een chronische aandoening wordt vastgesteld, krijgen zij te maken met een groot aantal gevolgen van deze aandoening, zoals symptomen, fysieke beperkingen, verminderde mogelijkheden in het ondernemen van sociale activiteiten en psychische klachten. Het proces waarin patiënten leren om te gaan met de beperkingen die zij ervaren, wordt in het algemeen opgevat als het proces van aanpassing aan de ziekte. In dit proefschrift wordt bestudeerd hoe dit aanpassingsproces verloopt bij patiënten met een chronisch obstructieve longaandoening (COPD) en patiënten met chronisch hartfalen (CHF). Aanpassing aan ziekte wordt in dit proefschrift geïnterpreteerd in termen van kwaliteit van leven (KvL). Wij hebben ervoor gekozen om patiënten met deze twee aandoeningen te onderzoeken, omdat beide veel voorkomende en chronische aandoeningen zijn. Verder zijn beide aandoeningen vergelijkbaar met betrekking tot de klinische kenmerken van de aandoeningen. In de eerste plaats hebben wij onderzocht wat de verschillen zijn in KvL tussen de patiënten met COPD en de patiënten met CHF. In de tweede plaats hebben wij de determinanten van aanpassing aan ziekte onderzocht, waarbij wij hebben bestudeerd wat de bijdrage is van respectievelijk medische en psychologische factoren aan de KvL van patiënten met COPD en CHF.

COPD is het gevolg van verschillende ziekteprocessen en wordt gekenmerkt door luchtwegobstructie en een verminderde longfunctie, die niet volledig reversibel is na het gebruik van medicatie. De diagnose COPD betreft zowel patiënten met chronische bronchitis als patiënten met longemfyseem. De meeste patiënten met COPD hebben last van klachten, zoals chronisch hoesten, dyspneu, sputumproductie, en een piepende ademhaling. De longfunctie van COPD patiënten neemt in de loop van de tijd af, waardoor ook de functionele status van deze patiënten verslechtert. Roken is wereldwijd de belangrijkste oorzaak van het ontstaan van COPD. COPD is één van de meest voorkomende medische aandoeningen en is wereldwijd de vierde doodsoorzaak. De verwachting is dat de prevalentie van COPD en de mortaliteit ten gevolge van COPD de komende jaren nog verder zullen toenemen.

Verbeteringen in de behandeling van hartpatiënten hebben ertoe geleid dat het aantal patiënten dat een hartinfarct overleeft is toegenomen. Op de langere termijn ontwikkelt een groot aantal van deze patiënten echter chronisch hartfalen (CHF). Hartfalen is een complex klinisch syndroom, dat het gevolg is van verschillende ziekteprocessen die kunnen leiden tot een verminderde pompfunctie van het hart. Deze verminderde pompfunctie van het hart kan veroorzaakt worden door een verminderde knijpkracht van het hart (verminderde linker ventrikel systolische functie) of een onvoldoende vulling van het ventrikel (diastolisch hartfalen). Symptomen van hartfalen zijn dyspneu en vermoeidheid, die kunnen leiden tot een verminderde inspanningscapaciteit, en het vasthouden van vocht in het lichaam, wat weer kan leiden tot vochtophoping in de longen, of in de buik, benen of voeten. In dit proefschrift hebben wij ons beperkt tot het onderzoeken van linker ventrikel systolisch hartfalen. Hartfalen is een progressieve aandoening, waarbij de linker ventrikelfunctie steeds verder afneemt. De belangrijkste oorzaken van hartfalen zijn hypertensie en coronaire hartziekten en de risicofactoren zijn een hogere leeftijd, diabetes, roken en obesitas. Hartfalen wordt gezien als een veel voorkomend en toenemend probleem voor de volksgezondheid. Het is een ernstige aandoening met een slechte prognose, die de levensduur van patiënten in sterke mate doet afnemen.

Om de psychologische aanpassing aan COPD en CHF binnen een uiteenlopende groep van patiënten te onderzoeken, hebben wij patiënten binnen verschillende behandelsettings onderzocht. Ten eerste hebben wij patiënten met COPD en CHF onderzocht die waren verwezen naar een revalidatiecentrum. Ten tweede hebben wij prevalente patiënten met COPD en CHF geïncludeerd die onder behandeling waren in een polikliniek. Het onderzoek dat wordt beschreven in dit proefschrift bestond uit twee meetmomenten. De patiënten met COPD en CHF die waren geïncludeerd in het revalidatiecentrum werden zowel voorafgaand aan als na afloop van het revalidatieprogramma onderzocht. De patiënten met COPD en CHF uit de polikliniek werden twee keer onderzocht met een interval van vier maanden. Vanaf januari 2001 tot en met juni 2002 werden de patiënten voor dit onderzoek benaderd.

Dit proefschrift is onderverdeeld in twee verschillende delen. In het eerste deel van dit proefschrift hebben wij het verband onderzocht tussen verschillende aspecten van persoonlijke controle en KvL bij patiënten met COPD en CHF. Verschillende variabelen van persoonlijke controle werden onderzocht, namelijk 'mastery', 'perceived health competence' en 'self-efficacy'. Met 'mastery' wordt de mate bedoeld waarin mensen controle ervaren over hun leven in het algemeen. Een vorm van controle die specifieker gerelateerd is aan de gezondheid van mensen is 'perceived health competence', die de controle die mensen ervaren over hun gezondheid inhoudt. 'Self-efficacy', tenslotte, verwijst naar het vertrouwen van mensen dat zij een bepaald gedrag kunnen vertonen om hun ziekte onder controle te houden. Het tweede deel van dit proefschrift beslaat de meer theoretische studie van het begrip KvL, gezondheid, en de verschillende onderliggende aspecten van gezondheid. In *hoofdstuk 7*, tenslotte, wordt een samenvatting gegeven van de belangrijkste resultaten en worden enkele kritische kanttekeningen geplaatst. Verder worden er theoretische en klinische implicaties van deze resultaten gegeven.

Deel 1

In *hoofdstuk 2* hebben wij ons gericht op de patiënten met COPD binnen ons onderzoek en hebben wij patiënten die waren verwezen voor revalidatie vergeleken met patiënten die onder behandeling waren in de polikliniek. Wij hebben onderzocht in hoeverre bij COPD patiënten de percepties van mastery en self-efficacy verbeterden tijdens revalidatie en in hoeverre deze percepties van persoonlijke controle gerelateerd waren aan betere resultaten van het revalidatieprogramma. De behandeling van COPD patiënten is deels afhankelijk van de inspanning van de patiënten om bepaalde 'ongezonde' gedragingen te veranderen. Voor het succes van longrevalidatie is het bijvoorbeeld van essentieel belang dat de patiënten stoppen met roken en meer aan lichaamsbeweging gaan doen. Roken is de belangrijkste oorzaak van het ontstaan en de progressie van COPD en is risicogedrag dat voor de meeste patiënten moeilijk te veranderen is. Om verbetering tijdens het revalidatieprogramma mogelijk te maken, zullen de patiënten gemotiveerd moeten zijn om hun gedrag bij te stellen. Echter, veel patiënten met COPD worden geconfronteerd met een uitgebreide en complexe problematiek en zijn door eerder mislukte pogingen om hun gedrag te veranderen in veel gevallen daartoe minder gemotiveerd. Eerder mislukte pogingen om hun ongezonde gedrag te veranderen heeft er bij veel patiënten toe geleid dat zij in mindere mate persoonlijke controle ervaren. Bovendien zijn de COPD patiënten die wij hebben onderzocht er, met betrekking tot hun longfunctie, tamelijk slecht aan toe. Hoewel longrevalidatie goede mogelijkheden biedt om deze meervoudige beperkingen van COPD patiënten te behandelen, verloopt de behandeling van deze patiënten niet altijd succesvol. Eerdere studies hebben laten zien dat percepties van persoonlijke effectiviteit of persoonlijke controle van invloed zijn op de motivatie van patiënten om moeite te doen voor het uitvoeren van bepaald gedrag. Verder is er een verband gelegd tussen deze percepties van persoonlijke controle en leefstijlveranderingen, zoals meer bewegen en stoppen met roken. Het is daarom goed mogelijk dat percepties van persoonlijke controle ook samenhangen met de resultaten van longrevalidatie. Bovendien spelen percepties van persoonlijke controle mogelijk ook een belangrijke rol in het tot stand brengen en vasthouden van effecten van revalidatie. Daarom hebben wij in de eerste plaats onderzocht of de KvL en de percepties van persoonlijke controle van patiënten met COPD verbeterden tijdens revalidatie, vergeleken met een referentiegroep bestaande uit COPD patiënten uit de polikliniek die niet waren verwezen naar het revalidatiecentrum. De resultaten van deze studie lieten zien dat de algemene KvL en de percepties van self-efficacy van de COPD patiënten verbeterden tijdens revalidatie, terwijl de referentiegroep geen verbeteringen liet zien in de variabelen die onderzocht werden. In de tweede plaats hebben wij onderzocht of verbeteringen in mastery en self-efficacy tijdens revalidatie samenhingen met een betere KvL na afloop van het revalidatieprogramma. De resultaten lieten zien dat veranderingen in self-efficacy samenhingen met een beter sociaal en psychisch functioneren na afloop van het revalidatieprogramma. Deze resultaten ondersteunen de verwachting dat longrevalidatie een positief effect heeft op de self-efficacy van patiënten met COPD. Aangezien de behandeling van COPD afhankelijk is van de mate waarin de patiënten zich verantwoordelijk voelen voor en bereid zijn tot het aangaan van bepaalde gedragsveranderingen, is het waarschijnlijk dat het verbeteren van de persoonlijke controle van patiënten met COPD een belangrijke factor is in de behandeling van deze patiënten.

In *hoofdstuk 3* worden de resultaten van patiënten met COPD en CHF uit de poliklinieken gepresenteerd. Met betrekking tot de klinische kenmerken van de aandoeningen zijn COPD en CHF in zekere zin vergelijkbaar: beide aandoeningen zijn progressief en worden gekenmerkt door kortademigheid en een verminderde inspanningscapaciteit. Hoewel patiënten met COPD en CHF vergelijkbare klachten ervaren, zijn er mogelijk verschillen tussen de aandoeningen in de mate waarin domeinen van KvL zijn aangetast door de ziekten, aangezien de onderliggende oorzaken voor de functionele beperkingen van COPD en CHF verschillend zijn. Toch is het mogelijk dat de factoren die bijdragen aan de KvL van patiënten met COPD en CHF vergelijkbaar zijn, dat wil zeggen, dat de mechanismen die de KvL verklaren vergelijkbaar kunnen zijn bij patiënten met COPD en CHF. Daarom hebben wij in de eerste plaats patiënten met COPD en CHF vergeleken met betrekking tot domeinen van KvL en percepties van persoonlijke controle. De resultaten van deze studie laten zien dat patiënten met CHF significant beter functioneren dan patiënten met COPD wat betreft hun fysiek en psychisch functioneren en hun perceived health competence. In de tweede plaats hebben wij onderzocht in hoeverre het zelfgerapporteerde fysiek functioneren van patiënten met COPD en CHF in de eerste plaats verklaard wordt door ziektespecifieke verschillen gerelateerd aan verschillen in diagnose, of dat ook meer generieke factoren, namelijk ernst van de aandoening en percepties van persoonlijke controle, bijdragen aan de verklaring van fysiek functioneren. In de eerste stap van de regressie-analyse hingen zowel ziektespecifieke factoren gerelateerd aan verschillen in diagnose, en een generieke factor, namelijk ernst van de aandoening, samen met fysiek functioneren. Echter, diagnose en ernst van de aandoening verklaarden geen extra variantie van zelfgerapporteerd fysiek functioneren nadat de variabelen van persoonlijke controle in de analyse waren opgenomen. Hoewel de groepen van elkaar verschilden in fysiek functioneren, bleek dat in beide groepen vergelijkbare factoren, namelijk ernst van de ziekte en self-efficacy, het sterkst samenhingen met fysiek functioneren. Deze resultaten wijzen erop dat niet alleen het verbeteren van fysiek functioneren, maar ook het verbeteren van de percepties van self-efficacy waarschijnlijk een belangrijk rol speelt in de behandeling van patiënten met COPD en CHF.

Deel 2

De resultaten uit *hoofdstuk 4* zijn gebaseerd op data uit de Groningen Longitudinal Aging Study (GLAS), waarin de determinanten van ziekte, beperkingen en welbevinden van ouderen werd onderzocht. Dit hoofdstuk richt zich op de relatie tussen domeinen van KvL en algemene KvL bij patiënten met acht verschillende chronische aandoeningen. Ondanks de toegenomen interesse van zowel klinische als sociaal-wetenschappelijke studies in het bestuderen van de KvL van chronisch zieken, bestaat er nog geen algemeen aanvaarde definitie van KvL. In dit hoofdstuk hebben wij het hiërarchisch model van KvL van Spilker gebruikt met als doel te onderzoeken wat de relaties zijn tussen domeinen van KvL en de algemene KvL van patiënten met acht verschillende chronische aandoeningen. Verder hebben wij deze verschillende groepen patiënten vergeleken in hun functioneren met betrekking tot domeinen van KvL en algemene KvL. Verschillende medische condities kunnen een verschillende invloed hebben op de domeinen van KvL van de patiënten, ten gevolge van ziektespecifieke kenmerken, zoals bepaalde symptomen of beperkingen. Vervolgens kan ook de relatie tussen de domeinen van KvL en de algemene KvL anders zijn bij verschillende aandoeningen. Daarom hebben wij deze relatie tussen domeinen van KvL en algemene KvL onderzocht bij patiënten met verschillende aandoeningen. Wij hebben in deze studie patiënten geselecteerd met één van de volgende acht aandoeningen zonder co-morbiditeit: longziekten, hartaandoeningen, hypertensie, diabetes mellitus, rugklachten, reumatoïde artritis, migraine of huidaandoeningen. Eerst hebben wij de chronisch zieke patiënten vergeleken met een groep gezonde (oudere) mensen. De resultaten laten zien dat patiënten met een longziekte, hartaandoening, rugklachten, reumatoïde artritis of migraine een slechter fysiek en sociaal functioneren rapporteerden dan de gezonde mensen. Met betrekking tot psychisch functioneren en algemene KvL bleek dat alleen patiënten met longziekten en migraine slechter functioneerden dan de gezonde mensen. Ten tweede hebben wij onderzocht of de samenhang van de domeinen fysiek, sociaal en psychisch functioneren met de algemene KvL verschillend was, en wat de totale bijdrage was van deze drie domeinen aan de algemene KvL van de patiënten. Het domein psychisch functioneren was gerelateerd aan de algemene KvL bij alle aandoeningen en bij de gezonde mensen. Alleen bij patiënten met longziekten en hypertensie droeg fysiek functioneren bij aan de verklaring van de algemene KvL. Sociaal functioneren hing alleen samen met de algemene KvL bij patiënten met rugklachten, reumatoïde artritis en migraine. Deze resultaten wijzen erop dat verschillende chronische aandoeningen een verschillende invloed hebben op de domeinen van KvL, wat met name geldt voor het psychisch domein van KvL, hoewel de algemene KvL voor de meeste aandoeningen niet verschilde van de gezonde groep. Blijkbaar zijn domeinen van KvL en algemene KvL twee verschillende manieren om KvL te interpreteren, aangezien de drie domeinen niet de totale hoeveelheid variantie van algemene KvL verklaarden.

Hoofdstuk 5 gaat specifieker in op het hiërarchisch model van Spilker en onderzoekt de relaties tussen parameters van KvL op de drie verschillende niveaus in het model. Dit hoofdstuk bouwt voort op het vorige hoofdstuk door nu het derde niveau van Spilkers model, namelijk de specifieke elementen van de KvL domeinen, toe te voegen en de relatie van dit derde niveau met de overige niveaus in het model verder uit te zoeken. Dit houdt in dat wij KvL hebben gemeten op het algemene niveau van levenskwaliteit, op het niveau van de domeinen fysiek, sociaal en psychisch functioneren en op het niveau van de onderliggende aspecten van de KvL domeinen. Hierbij hebben wij het derde niveau van Spilkers model geoperationaliseerd als symptomen van dyspneu, die beschouwd kunnen worden als specifieke elementen van het fysieke domein van KvL. Wij hebben voor symptomen van dyspneu gekozen, omdat dit belangrijke symptomen voor zowel COPD als

CHF zijn. Bovendien hebben wij Spilkers model getoetst door middel van 'structural equation modelling'. Dit is een statistische techniek om het verband tussen verschillende variabelen in een hypothetisch model te toetsen. In de eerste plaats hebben wij onderzocht of symptomen van dyspneu (niveau 3) van invloed waren op de algemene KvL (niveau 1), via de domeinen van KvL fysiek, sociaal en psychisch functioneren (niveau 2). Symptomen van dyspneu hingen zowel direct als indirect, via de KvL domeinen fysiek en sociaal functioneren, samen met de algemene KvL. Ten tweede hebben wij onderzocht in hoeverre dit verband tussen dyspneu en algemene KvL vergelijkbaar was bij patiënten met COPD en patiënten met CHF. Hierbij was onze hypothese dat er sprake is van een hiërarchie in de onderlinge samenhang tussen de domeinen van KvL op het tweede niveau van Spilkers model, dat wil zeggen, wij verwachtten dat het fysieke domein van invloed was op de algemene KvL via de domeinen sociaal en psychisch functioneren. De resultaten ondersteunden onze hypothese ten aanzien van een hiërarchische ordening van de domeinen van KvL: het verband tussen fysiek functioneren en algemene KvL werd gemediëerd door sociaal functioneren bij patiënten met CHF en bij patiënten met COPD door sociaal en psychisch functioneren. Dit houdt in dat, ondanks de kleine verschillen tussen de modellen voor patiënten met COPD en CHF, de directe en indirecte verbanden tussen dyspneu en algemene KvL tamelijk vergelijkbaar waren. Opmerkelijk is dat symptomen van dyspneu ook rechtstreeks van invloed waren op de algemene KvL, wat wijst op het belang van interventies gericht op dit niveau van KvL. Verder kan geconcludeerd worden dat, hoewel de oorzaken van beide aandoeningen van elkaar verschillen, de relaties tussen symptomen, domeinen van KvL en algemene KvL vergelijkbaar zijn bij patiënten met COPD en CHF.

In *hoofdstuk 6* worden de relaties tussen verschillende parameters van gezondheid en de algemene gezondheidsbeleving van de patiënten als afhankelijke variabele bestudeerd. In het bijzonder wordt in dit hoofdstuk onderzocht wat het verband is tussen objectieve en subjectieve parameters van gezondheid bij patiënten met COPD en patiënten met CHF. In deze studie hebben wij het conceptuele model van Wilson & Cleary getoetst, dat de verschillende consequenties van een aandoening voor een patiënt omvat en daarbij verschillende aspecten van gezondheid onderscheidt, van biologische of fysiologische factoren als éne uiterste tot KvL als andere uiterste. Wij hebben dit model onderzocht, omdat het zowel objectieve indicatoren van gezondheid als meer subjectieve factoren van gezondheid, zoals de beleving van gezondheid en algemene KvL, in zich verenigt. In feite vormt dit model de integratie van het biomedisch model, dat gehanteerd wordt in klinische studies, met het sociaal-wetenschappelijk model uit psychologische studies en bovendien overlapt dit model op bepaalde punten met het eerder gebruikte model van Spilker. Het doel van deze studie was te onderzoeken wat het verband is tussen objectieve en subjectieve parameters van gezondheid bij patiënten met COPD en patiënten met CHF. In het bijzonder hebben wij onderzocht in hoeverre het verband tussen objectieve parameters (longfunctie voor COPD en linker ventrikelfunctie voor CHF) en de algemene gezondheidsbeleving gemediëerd werd door symptomen van dyspneu en fysiek functioneren. De resultaten tonen aan dat de relatie tussen objectieve gezondheid, namelijk longfunctie of linker ventrikelfunctie, en subjectieve gezondheid, namelijk zelfgerapporteerd fysiek functioneren, niet gemediëerd werd door symptomen van dyspneu. De relatie tussen longfunctie of linker ventrikelfunctie en dyspneu met algemene gezondheidsbeleving werd gemediëerd door zelfgerapporteerd fysiek functioneren van patiënten met COPD en CHF. Het tweede doel van deze studie was te onderzoeken op welk niveau in het model percepties van persoonlijke controle gerelateerd waren aan de parameters van gezondheid bij patiënten met COPD en CHF. Perceived health competence was gerelateerd aan dyspneu en algemene gezondheidsbeleving bij zowel patiënten met COPD als patiënten met CHF. Opmerkelijk is dat niet alleen fysiek functioneren, maar ook percepties van persoonlijke controle samenhingen met de algemene beleving van de patiënten van hun gezondheid in het algemeen. Hoewel de COPD patiënten slechter functioneerden dan de patiënten met CHF met betrekking tot alle zelfgerapporteerde parameters van gezondheid in het model, laat deze studie zien dat de onderlinge verbanden tussen de parameters in het model vergelijkbaar waren bij patiënten met COPD en CHF. Hoewel de onderliggende oorzaken van COPD en CHF verschillend zijn, lijken de processen waardoor de verschillende aspecten van gezondheid onderling samenhangen vergelijkbaar te zijn bij patiënten met COPD en patiënten met CHF.

Hoofdstuk 7 geeft een samenvatting van de belangrijkste bevindingen in dit proefschrift en bespreekt de implicaties van deze resultaten. Het ontstaan van een chronische aandoening leidt vaak tot psychologische stress, waarmee de patiënten moeten leren omgaan. Echter, niet alle patiënten zijn in staat tot het ontwikkelen van strategieën om zich aan te passen aan de ziekte, hetgeen een negatief effect heeft op hun KvL en welbevinden. Daarom is het belangrijk om meer inzicht te verwerven in dit proces van adaptatie en de factoren die in verband staan met adaptatie. KvL kan worden opgevat als één van de belangrijkste uitkomsten van dit proces van adaptatie. In dit proefschrift hebben wij de KvL van patiënten met COPD en CHF bestudeerd met als doel te onderzoeken hoe deze patiënten zich hebben aangepast aan hun ziekte. De eerste onderzoeksvraag van dit proefschrift betrof het verschil tussen patiënten met COPD en CHF met betrekking tot de uitkomsten van dit proces van adaptatie, gemeten aan de hand van hun KvL. Dit geeft aan dat patiënten met COPD en CHF van elkaar verschillen in het niveau van functioneren op verschillende aspecten van KvL. Ongeacht deze verschillen tussen beide groepen patiënten, bleek dat de onderliggende mechanismen die de KvL van de patiënten kunnen verklaren vergelijkbaar waren bij patiënten met COPD en patiënten met CHF. Tussen chronische aandoeningen bestaan verschillen in de mate waarin de KvL van de patiënten is aangetast, terwijl vergelijkbare processen leiden tot dit niveau van KvL van de patiënten. De tweede onderzoeksvraag van dit proefschrift betrof de medische en psychologische factoren die gerelateerd zijn aan adaptatie aan ziekte. Met betrekking tot deze onderzoeksvraag hebben wij geconcludeerd dat zowel medische factoren, namelijk longfunctie en linker ventrikelfunctie, en percepties van persoonlijke controle van invloed waren op het proces van adaptatie bij patiënten met COPD en CHF. Beide zijn echter gerelateerd aan verschillende aspecten van dit aanpassingsproces. Longfunctie en linker ventrikelfunctie hingen samen met de fysieke aspecten van het functioneren, terwijl persoonlijke controle gerelateerd was aan zowel de fysieke als de psychosociale aspecten van het functioneren. Longfunctie en linker ventrikelfunctie zijn belangrijke determinanten van de mate van fysieke beperking, maar laten niet zien hoe deze beperkingen vervolgens van invloed zijn op de psychische en sociale aspecten van het leven van patiënten en op hun algemeen welbevinden.

Afgezien van deze conclusies, wordt in *hoofdstuk 7* ook een aantal methodologische zaken besproken met betrekking tot het design en de steekproef van de studie. Verder wordt een aantal theoretische en klinische implicaties van de studie genoemd. Deze implicaties worden besproken aan de hand van drie centrale thema's. In de eerste plaats waren de ziektespecifieke en generieke aspecten in de aanpassing aan ziekte een belangrijk thema in het onderzoek van dit proefschrift. Wij hebben in dit onderzoek zowel ziektespecifieke als generieke factoren in het aanpassingsproces gevonden. In de algemene discussie werd daarom benadrukt dat ook de behandeling van patiënten met COPD en CHF uit zowel ziektespecifieke als generieke onderdelen zou kunnen bestaan. Toekomstig onderzoek zou zich vervolgens moeten richten op de vraag welke kenmerken van ziekten de verschillen in KvL tussen patiënten met verschillende ziekten veroorzaken. Op deze manier wordt duidelijk welke delen van de behandeling voor verschillende aandoeningen toepasbaar zijn en welke ziektespecifiek aangeboden moeten worden. Het tweede thema betrof de conceptuele studie van het begrip KvL en de elementen waaruit dit is opgebouwd. Twee specifieke modellen, van KvL en van verschillende gezondheidsparameters, werden beschreven en onderzocht en vormden de basis voor dit proefschrift. De resultaten in dit proefschrift geven meer inzicht in de mate waarin de verschillende niveaus van KvL door aandoeningen worden aangetast en in de onderlinge relaties tussen deze niveaus van KvL. In de discussie wordt beargumenteerd dat de behandeling van patiënten met COPD en CHF idealiter op alle niveaus van KvL gericht zou moeten worden. In toekomstig onderzoek zou het relevant zijn deze verbanden tussen de verschillende niveaus van KvL longitudinaal te onderzoeken vanaf het moment dat de patiënten de eerste symptomen van hun ziekte ervaren. Het derde thema had betrekking op de relaties tussen variabelen van persoonlijke controle met KvL, aangezien in eerdere studies is aangetoond dat persoonlijke controle een belangrijke determinant is van KvL en van welbevinden van chronisch zieke patiënten. In dit onderzoek werd gevonden dat percepties van self-efficacy en perceived health competence een belangrijke rol spelen in de aanpassing aan COPD en CHF. Het meer benadrukken van het verbeteren van de persoonlijke controle in de behandeling van deze patiënten heeft mogelijk een positief effect op de KvL van deze patiënten. Het zou interessant zijn om verder te onderzoeken in hoeverre deze specifieke variabelen van persoonlijke controle ook van belang zijn in de aanpassing aan andere aandoeningen.

We weten niet wat de bergen
vandaag met ons zullen beginnen.
We hebben voedsel en drank en
stevige schoenen. En we vertrekken.

De top en niets anders verwacht ons.
Een nieuw uitzicht op de wereld. En
misschien komt een moment waarop
we niet hoger meer durven en

evenmin nog terug. Wanneer het
duister valt en de bergen rondom
dus toch ongenaakbaar en wij die
dat altijd al hebben geweten.

Marc Tritsmans

Dankwoord

Toen ik vijf jaar geleden aan dit onderzoek begon, had ik een ideaalbeeld van hoe het onderzoek zou moeten worden opgezet en uitgevoerd. Gaandeweg ontdekte ik dat het in de praktijk vaak niet zo gaat als je van achter je bureau hebt uitgedacht. Het was tijdens het uitvoeren van dit onderzoek gelukkig noodzakelijk om achter mijn computer vandaan te komen, anders had ik een stuk minder geleerd. Het onderzoeken van twee patiëntenpopulaties met verschillende aandoeningen, die bovendien in zowel een poliklinische als revalidatie setting werden onderzocht, zorgde voor een ingewikkelde logistiek van het onderzoek. Een groot gedeelte van mijn tijd was ik bezig met het includeren van patiënten in het AZG, in het Martiniziekenhuis en in Beatrixoord. Het voordeel daarvan was dat ik veel contact heb gehad met patiënten en een beeld heb kunnen krijgen van de uiteenlopende gevolgen die een chronische aandoening met zich mee kan brengen. Op deze manier kon ik de theorie spiegelen aan de praktijk en ook de resultaten van de Epsylonstudie binnen een breder kader plaatsen, wat voor mij een meerwaarde in het onderzoek heeft opgeleverd.

Bij het nadenken over aanpassing aan ziekte kwam de metafoor van het beklimmen van een berg bij mij op. Niet alleen omdat het proces van leren omgaan met de beperkingen van een chronische ziekte moeizaam kan zijn, maar ook omdat dit proces kan leiden tot een nieuw perspectief, een nieuw 'uitzicht', op wat nog wel mogelijk is in het leven. Om deze reden heb ik, naast het feit dat ik zelf een groot liefhebber ben van wandelen in de bergen, gekozen voor de berg op de omslag van dit proefschrift. Ook het schrijven van een proefschrift zou in zekere zin gezien kunnen worden als het beklimmen van een berg. In feite sta ik nu op de top van de berg en kijk ik terug op een wandeling die zeer de moeite waard was; hier en daar was het heftig klimmen, maar het werd nooit echt te veel en gelukkig wordt klimmen altijd beloond met een mooi uitzicht. Bovendien klom ik nooit alleen.

Veel mensen hebben bijgedragen aan de totstandkoming van dit proefschrift of hebben mij tijdens het promotietraject op een of andere wijze begeleid, geholpen of gesteund. Al deze mensen wil ik op deze manier heel hartelijk bedanken. Een aantal van mijn 'reisgenoten' wil ik hier, aan het einde van mijn proefschrift, graag persoonlijk noemen.

In de eerste plaats had ik dit proefschrift nooit kunnen schrijven zonder de medewerking van veel patiënten, die iedere keer weer de moeite hebben genomen om de uitgebreide vragenlijsten in te vullen. Verder ben ik vaak door patiënten gebeld of geschreven om mij van uitgebreidere informatie te voorzien, wat ik heel waardevol heb gevonden.

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Verschillende afdelingen uit de centra waarin het onderzoek is uitgevoerd hebben bijgedragen aan het uitdenken of uitvoeren van de Epsylonstudie. Graag wil ik iedereen bedanken van de afdeling longziekten en het thoraxcentrum in het AZG, de afdelingen longrevalidatie, hartrevalidatie en OKER in Beatrixoord en de afdeling longziekten in het Martiniziekenhuis. In het bijzonder wil ik hier bedanken Nick ten Hacken, Johan Wempe, Verona Otten, Niels de Voogd, Johan Brügemann, Mieke Oosterwijk, René Aalbers en Hanneke van der Woude. Jullie hebben me wegwijs gemaakt in de verschillende klinieken en me geholpen bij het opzetten van het onderzoek. Daarnaast hebben jullie een belangrijke bijdrage geleverd aan één of meer artikelen in mijn proefschrift, waarvoor ik jullie heel hartelijk wil bedanken. Verder wil ik de leden van GRIAC onder leiding van Prof. dr. Dirkje Postma danken voor het feit dat ik kon participeren in de dinsdagmiddagbesprekingen in het AZG.

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Rosemarie Arnold
Groningen, juli 2004

Northern Centre for Healthcare Research (NCH) and previous dissertations

The Northern Centre for Healthcare Research (NCH) was founded in 1986 as a research institute of the University of Groningen (RUG), the Netherlands. Researchers from both the Medical and the Social Faculty, with various professional backgrounds, are members of the NCH. These include medical sociologists, medical doctors, psychologists and human movement scientists. Research of the NCH is aimed at optimising quality of life of patients and quality of healthcare, and focuses on (a) determinants of health and illness, (b) consequences of illness, (c) the effects of medical treatment and decision making, and (d) the evaluation of health services and various types of interventions. At the time that this thesis is published, the NCH comprises five research programmes.

Until 1998, the NCH covered two research programmes, i.e. 'Determinants of Health' and 'Medical Decision Making and Evaluation of Healthcare'. The first programme was reformulated in 1996 and was continued as 'Disorder, Disability and Quality of Life' (DDQ). Hence, previous dissertations in this area are listed as part of the present DDQ-programme. In 1998 the second programme was subdivided into two new programmes, i.e. 'Public Health and Public Health Services Research' and 'Rational Drug Use'.

Dissertations published earlier within the second programme are listed retrospectively under these new headings. In 1998, two new programmes, 'Rehabilitation Programs Research' and 'Research in Motor Behaviour', were formulated and officially integrated in the NCH in January 1999. The dissertations which have been accomplished since the start of the programmes in 1998 are included in the list. In 2000 the Department of General Practice joined the NCH and together with the Rational Drug Use group initiated a new research programme, i.e. 'Research in Evidence Based Medicine'.

More information regarding the institute and its research can be obtained from our internet site: http://www.med.rug.nl/nch.

Disorder, Disability and Quality of Life

Pool G (2003) *Surviving testicular cancer; sexuality and other existential issues.*
PROMOTORES: prof dr HBM van de Wiel, prof dr DTh Sleijfer,
prof dr HJ Hoekstra
CO-PROMOTOR: dr MF van Driel

Stiegelis HE (2003) *A life less ordinary; cognitive adaptation and psychological functioning among cancer patients treated with radiotherapy.*
PROMOTORES: prof dr R Sanderman, prof dr AP Buunk
CO-PROMOTOR: dr M Hagedoorn

Heuvel ETP van den (2002) *Supporting caregivers of stroke patients; an intervention study.*
PROMOTORES: prof dr B Meyboom-de Jong, prof dr R Sanderman
CO-PROMOTOR: dr LP de Witte
REFERENT: dr LM Schure

Schroevers MJ (2002) *Short- and long-term adaptation to cancer; a comparison of patients with the general population.*
PROMOTOR: prof dr R Sanderman
REFERENT: dr AV Ranchor

Hoekstra-Weebers JEHM (2000) *Parental adaptation to pediatric cancer.*
PROMOTORES: prof dr EC Klip, prof dr WA Kamps
REFERENT: dr JPC Jaspers

Doeglas DM (2000) *Functional ability, social support and quality of life: a longitudinal study in patients with early rheumatoid arthritis.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr R Sanderman
CO-PROMOTOR: dr ThPBM Suurmeijer

Nijboer C (2000) *Caregiving to patients with colorectal cancer: a longitudinal study on caregiving by partners.*
PROMOTORES: prof dr GAM van den Bos, prof dr R Sanderman
CO-PROMOTOR: dr AHM Triemstra

Tiesinga LJ (1999) *Fatigue and Exertion Fatigue: from description through validation to application of the Dutch Fatigue Scale (DUFS) and the Dutch Exertion Fatigue Scale (DEFS).*
PROMOTORES: prof dr WJA van den Heuvel, prof dr ThWN Dassen
CO-PROMOTOR: dr RJG Halfens

Jong GM de (1999) *Stress, stress management and issues regarding implementation.*
PROMOTORES: prof dr PMG Emmelkamp, prof dr JL Peschar
REFERENT: dr R Sanderman

Alberts JF (1998) *The professionalized patient: sociocultural determinants of health services utilization.*
PROMOTOR: prof dr WJA van den Heuvel
REFERENT: dr R Sanderman

Eijk LM van (1997) *Activity and well-being in the elderly.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr SM Lindenberg
REFERENT: dr GIJM Kempen

Nieboer AP (1997) *Life-events and well-being: a prospective study on changes in well-being of elderly people due to a serious illness event or death of the spouse.*
PROMOTORES: prof dr SM Lindenberg, prof dr J Ormel
Scaf-Klomp W (1997) *Screening for breast cancer: attendance and psychological consequences.*
PROMOTOR: prof dr WJA van den Heuvel
REFERENT: dr R Sanderman
Zwanikken CP (1997) *Multiple sclerose: epidemiologie en kwaliteit van leven.*
PROMOTOR: prof dr J Minderhoud
CO-PROMOTORES: dr JW Groothoff, dr ThPBM Suurmeijer
Kooiker SE (1996) *Illness in everyday life: a health diary study of common symptoms and their consequences.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr J van der Zee
Krol B (1996) *Quality of life in rheumatoid arthritis patients: the relation between personality, social support and depression.*
PROMOTOR: prof dr WJA van den Heuvel
REFERENTEN: dr R Sanderman, dr ThPBM Suurmeijer
Ruiter JH de (1995) *Sociale ondersteuning en kwaliteit van leven bij patiënten met kanker.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr H Schraffordt Koops
REFERENTEN: dr FLP van Sonderen, dr R Sanderman
Steverink N (1995) *Zo lang mogelijk zelfstandig: naar een verklaring van verschillen ten aanzien van opname in een verzorgingstehuis onder fysiek kwetsbare ouderen.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr TAB Snijders, prof dr J Ormel
Uitenbroek DG (1995) *Exercise behaviour.*
PROMOTOR: prof dr WJA van den Heuvel
Linden-van den Heuvell GFEC van (1994) *Voorbereiding op medische ingrepen.*
PROMOTOR: prof dr EC Klip
Linschoten CP van (1994) *Gezondheidsbeleving van ouderen: een longitudinale studie.*
PROMOTOR: prof dr WJA van den Heuvel
CO-PROMOTOR: dr J Ormel
Oosterhuis A (1994) *De gedragstherapeutische behandeling van slaapklachten.*
PROMOTOR: prof dr EC Klip
Ranchor AV (1994) *Social class, psychosocial factors and disease: from description towards explanation.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr AP Buunk
REFERENTEN: dr R Sanderman, dr J Bouma
Reitsma B (1994) *The end of the line? Evaluation of a multidisciplinary team approach to chronic pain.*
PROMOTORES: prof dr EC Klip, prof dr JWF Beks, prof dr JP Hennis
Gerritsen JC (1993) *Onafhankelijkheid van ouderen: mogelijkheden en voorwaarden.*
PROMOTOR: prof dr WJA van den Heuvel

Heyink JW (1992) *Levertransplantatie: psycho-sociale aspecten.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr MJH Slooff
REFERENT: dr Tj Tijmstra

Sonderen FLP van (1991) *Het meten van sociale steun.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr FN Stokman
REFERENT: dr J Ormel

Kempen GIJM (1990) *Thuiszorg voor ouderen: een onderzoek naar de individuele determinanten van het gebruik van wijkverpleging en/of gezinsverzorging op verzorgend en huishoudelijk gebied.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr W Molenaar
REFERENT: dr ThPBM Suurmeijer

Sanderman R (1988) *Life events, mediating variables and psychological distress: a longitudinal study.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr PE Boeke, prof dr PMG Emmelkamp
REFERENT: dr J Ormel

Public Health and Public Health Services Research

Reneman MF (2004) *Functional capacity evaluation in patients with chronic low back pain; reliability and validity.*
PROMOTORES: prof dr JW Groothoff, prof dr JHB Geertzen
CO-PROMOTOR: dr PU Dijkstra

Bâra-Ionilã C-A (2003) *The Romanian health care system in transition from the users' perspective.*
PROMOTORES: prof dr WJA van den heuvel, prof dr JAM Maarse
CO-PROMOTOR: dr JP van Dijk

Lege W de (2002) *Medische consumptie in de huisartspraktijk op Urk.*
PROMOTORES: prof dr D Post, prof dr JW Groothoff

Hoekstra EJ (2002) *Arbeidsbemiddeling met behulp van Supported Employment als interventie bij de reïntegratie van chronisch zieken; de rol van de arbeidsbemiddelaar, chronisch zieke en werkgever.*
PROMOTORES: prof dr JW Groothoff, prof dr K Sanders, prof dr WJA van den Heuvel, prof dr D Post

Enk JG van (2002) *Determinants of use of healthcare services in childhood.*
PROMOTORES: prof dr D Post, prof dr AJP Veerman, prof dr WJA van den Heuvel

Gecková A (2002) *Inequality in health among Slovak adolescents.*
PROMOTORES: prof dr D Post, prof dr JW Groothoff
REFERENT: dr JP van Dijk

Dijk JP van (2001) *Gemeentelijk gezondheidsbeleid; omvang en doelgerichtheid.*
PROMOTORES: prof dr D Post, prof dr M Herweijer, prof dr JW Groothoff

Middel LJ (2001) *Assessment of change in clinical evaluation.*
PROMOTOR: prof dr WJA van den Heuvel
REFERENT: dr MJL de Jongste

Bijsterveld HJ (2001) *Het ouderenperspectief op thuiszorg; wensen en behoeften van ouderen ten aanzien van de thuis(zorg)situatie in Friesland.*
PROMOTORES: prof dr D Post, prof dr B Meyboom-de Jong
REFERENT: dr J Greidanus

Dijkstra GJ (2001) *De indicatiestelling voor verzorgingshuizen en verpleeghuizen.*
PROMOTORES: prof dr D Post, prof dr JW Groothoff

Dalen IV van (2001) *Second opinions in orthopaedic surgery: extent, motives, and consequences.*
PROMOTORES: prof dr JR van Horn, prof dr PP Groenewegen, prof dr JW Groothoff

Beltman H (2001) *Buigen of barsten? Hoofdstukken uit de geschiedenis van de zorg aan mensen met een verstandelijke handicap in Nederland 1945-2000.*
PROMOTORES: prof dr D Post, prof dr AThG van Gennep

Pal TM (2001) *Humidifiers disease in synthetic fiber plants: an occupational health study.*
PROMOTORES: prof dr JGR de Monchy, prof dr D Post, prof dr JW Groothoff

Goossen WTF (2000) *Towards strategic use of nursing information in the Netherlands.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr ThWN Dassen, prof dr ir A Hasman

Hospers JJ (1999) *Allergy and airway hyperresponsiveness: risk factors for mortality.*
PROMOTORES: prof dr D Post, prof dr DS Postma, prof dr ST Weiss

Wijk P van der (1999) *Economics: Charon of Medicine?*
PROMOTORES: prof dr WJA van den Heuvel, prof dr L Koopmans, prof dr FFH Rutten
REFERENT: dr J Bouma

Dijkstra A (1998) *Care dependency: an assessment instrument for use in long-term care facilities.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr ThWN Dassen

Tuinstra J (1998) *Health in adolescence: an empirical study of social inequality in health, health risk behaviour and decision making styles.*
PROMOTORES: prof dr D Post, prof dr WJA van den Heuvel
CO-PROMOTOR: dr JW Groothoff

Mink van der Molen AB (1997) *Carpale letsels: onderzoek naar de verzuimaspecten ten gevolge van carpale letsels in Nederland 1990-1993.*
PROMOTORES: prof dr PH Robinson, prof WH Eisma
CO-PROMOTOR: dr JW Groothoff
REFERENT: dr GJP Visser

Mulder HC (1996) *Het medisch kunnen: technieken, keuze en zeggenschap in de moderne geneeskunde.*
PROMOTOR: prof dr WJA van den Heuvel

Dekker GF (1995) *Rugklachten-management-programma bij de Nederlandse Aardolie Maatschappij B.V.: ontwerp, uitvoering en evaluatie.*
PROMOTORES: prof dr D Post, prof WH Eisma
CO-PROMOTOR: dr JW Groothoff
Puttiger PHJ (1994) *De medische keuring bij gebruik van persluchtmaskers.*
PROMOTORES: prof dr D Post, prof dr WJA Goedhard
CO-PROMOTOR: dr JW Groothoff
Engelsman C & Geertsma A (1994) *De kwaliteit van verwijzingen.*
PROMOTORES: prof dr WJA van den Heuvel, prof dr FM Haaijer-Ruskamp, prof dr B Meyboom-de Jong
Lucht F van der (1992) *Sociale ongelijkheid en gezondheid bij kinderen.*
PROMOTOR: prof dr WJA van den Heuvel
REFERENT: dr JW Groothoff

Research in Evidence Based Medicine

Pont LG (2002) *Assessing the quality of prescribing in general practice.*
PROMOTORES: prof dr FM Haaijer-Ruskamp, prof dr WH van Gilst, prof dr T van der Molen
Bemelmans WJE (2001) *Prevention of coronary heart disease by nutritional interventions. Impact of nutritional education in groups and supplementation with alpha-linolenic acid.*
PROMOTOR: prof dr B Meyboom-de Jong
CO-PROMOTOR: dr JF May
REFERENTEN: dr J Broer, dr EJM Feskens, dr FW Siero, dr AJ Smit
Veninga CCM (2000) *Improving prescribing in general practice.*
PROMOTOR: prof dr FM Haaijer-Ruskamp
REFERENT: dr P Denig
Veehof LJG (1999) *Polypharmacy in the elderly.*
PROMOTORES: prof dr B Meyboom-de Jong, prof dr FM Haaijer-Ruskamp
Vries SO de (1998) *Management strategies for intermittent claudication.*
PROMOTOR: prof dr MGM Hunink
REFERENT: dr JB Wong
Bosch JL (1997) *Outcome assessment of the percutaneous treatment of lilac artery occlusive disease.*
PROMOTORES: prof dr MGM Hunink, prof dr WPThM Mall, prof dr L Koopmans
Dijkers FW (1997) *Repeat prescriptions: a study in general practice in the Netherlands.*
PROMOTORES: prof dr B Meyboom-de Jong, prof dr FM Haaijer-Ruskamp, prof dr AF Casparie
Trigt AM van (1995) *Making news about medicines.*
PROMOTORES: prof dr TFJ Tromp, prof dr FM Haaijer-Ruskamp

Boerkamp E (1995) *Assessing professional services quality: an application in health care.*
PROMOTORES: prof dr JC Reuijl, prof dr FM Haaijer-Ruskamp
Denig P (1994) *Drug choice in medical practice: rationals, routines, and remedies.*
PROMOTORES: prof dr FM Haaijer-Ruskamp, prof dr H Wesseling
Jong-van den Berg LTW de (1992) *Drug utilization studies in pregnancy: what can they contribute to safety assessment?*
PROMOTORES: prof dr MNG Dukes, prof dr H Wesseling
REFERENT: dr FM Haaijer-Ruskamp
Zijlstra IF (1991) *De regionaal klinisch farmacoloog.*
PROMOTORES: prof dr H Wesseling, prof dr FWJ Gribnau, prof dr C van Weel
REFERENTEN: dr FM Haaijer-Ruskamp, dr H Wollersheim

Rehabilitation Programs Research (from 1998 onwards)

Dekker R (2004) *Long-term outcome of sports injuries.*
PROMOTORES: prof dr HJ ten Duis, prof WH Eisma, prof dr JW Groothoff
CO-PROMOTOR: dr CK van der Sluis
Schegget-Slaterus MJ ter (2004) *The quality of expert advice in relation to the act on facilities for the handicapped.*
PROMOTORES: prof dr JW Groothoff, prof WH Eisma
Schönherr MC (2003) *Functional outcome after spinal cord injury.*
PROMOTORES: prof WH Eisma, prof dr JW Groothoff
Sturms LM (2003) *Pediatric traffic injuries; consequences for the child and the parents.*
PROMOTORES: prof WH Eisma, prof dr HJ ten Duis, prof dr JW Groothoff
CO-PROMOTOR: dr CK van der Sluis
Meijer JWM (2002) *The diabetic foot syndrome; diagnosis and consequences.*
PROMOTORES: prof WH Eisma, prof dr JW Groothoff
CO-PROMOTORES: dr TP Links, dr AJ Smit
Schoppen T (2002) *Functional outcome after a lower limb amputation.*
PROMOTORES: prof WH Eisma, prof dr JW Groothoff, prof dr LNH Göeken
REFERENTEN: dr AM Boonstra, dr J de Vries
Rommers GM (2000) *The elderly amputee: rehabilitation and functional outcome.*
PROMOTOR: prof WH Eisma
CO-PROMOTOR: dr JW Groothoff
Halbertsma JPK (1999) *Short hamstrings & stretching: a study of muscle elasticity.*
PROMOTORES: prof WH Eisma, prof dr LNH Göeken
CO-PROMOTOR: dr JW Groothoff
REFERENT: dr ir AL Hof

Geertzen JHB (1998) *Reflex sympathetic dystrophy: a study in the perspective of rehabilitation medicine.*
PROMOTORES: prof WH Eisma, prof dr HJ ten Duis
CO-PROMOTOR: dr JW Groothoff
REFERENT: dr PU Dijkstra

Sluis CK van der (1998) *Outcomes of major trauma.*
PROMOTORES: prof dr HJ ten Duis, prof WH Eisma

Research in Motor Behaviour (from 1998 onwards)

Kamsma YPT (2002) *Functional Reorganisation of basic motor actions in Parkinson's disease. Problem analysis, development and evaluation of a compensatory strategy training.*
PROMOTORES: prof dr P Rispens, prof dr WH Brouwer

Stevens M (2001) *Groningen Active Living Model (GALM): development and initial validation.*
PROMOTOR: prof dr P Rispens
REFERENTEN: dr KAPM Lemmink, dr MHG de Greef

Lettinga AT (2000) *Diversity in neurological physiotherapy: a comparative analysis of clinical and scientific practices.*
PROMOTORES: prof dr P Rispens, prof dr PJM Helders, prof dr A Mol

Heuvelen MJG van (1999) *Physical activity, physical fitness and disability in older persons.*
PROMOTOR: prof dr P Rispens
CO-PROMOTORES: dr WH Brouwer, dr GIJM Kempen
REFERENT: dr MHG de Greef

Berkhuysen MA (1999) *Toward tailor-made cardiac rehabilitation: getting at the heart of the matters.*
PROMOTORES: prof dr AP Buunk, prof dr P Rispens
REFERENT: dr R Sanderman