Chronic Obstructive Pulmonary Disease

Patients’ Perspectives, Impact of the Disease and Utilization of Spirometry

MATS ARNE
Dissertation presented at Uppsala University to be publicly examined in Rudbecksalen, Rudbecklaboratoriet, Dag Hammerskjölds väg 20, Uppsala, Friday, April 16, 2010 at 13:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in Swedish.

Abstract

The overall aim of this thesis was to describe subjects with chronic obstructive pulmonary disease (COPD) from different perspectives. Focus was on patients at the time of diagnosis, impact of the disease in comparison to other chronic diseases, factors associated with good health and quality of life (QoL), and diagnostic spirometry in clinical practice.

Methods: Qualitative method, grounded theory, was used to analyse patients’ perspectives at the time of diagnosis in a primary care setting (n=10). Public health surveys in the general population were used to compare chronic diseases (n=10,755) and analyse factors associated with health outcomes in COPD (n=1,475). Medical records and spirometry reports, from primary and secondary care, were analysed to assess diagnosis of COPD in clinical practice (n=533).

Results: In clinical practice, 70% of patients at the time of diagnosis of COPD lacked spirometry results confirming the diagnosis. Factors related to consequences of smoking, shame and restrictions in physical activity (PA) in particular, were described by patients at the time of diagnosis of COPD. In general subjects with COPD (84%), rheumatoid arthritis (74%) and diabetes mellitus (72%) had an activity level considered too low to maintain good health. In COPD, the most important factor associated with good health and quality of life was a high level of PA. Odds ratios (OR (95%CI)) varied from 1.90 (1.47-2.44) to 7.57 (4.57-12.55) depending on the degree of PA, where subjects with the highest PA level had the best health and QoL.

Conclusions: Subjects with COPD need to be diagnosed at an early stage, and health professionals should be aware that feelings of shame could delay patients from seeking care and thus obtaining a diagnosis. The use of spirometry and the diagnostic quality should be emphasised. In patients with COPD greater attention should be directed on increasing the physical activity level, as patients with a low level of physical activity display worse health and quality of life.

Keywords: chronic disease, chronic obstructive pulmonary disease, diabetes mellitus, diagnosis, health status, spirometry, physical activity, public health survey, qualitative method, quality of life, rheumatoid arthritis.

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List of papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


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<td>6MWD</td>
<td>Six minute walking distance</td>
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<td>ANOVA</td>
<td>Analysis of variance</td>
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<td>ATS</td>
<td>American Thoracic Society</td>
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<td>BMI</td>
<td>Body Mass Index</td>
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<td>CDUST</td>
<td>Collaboration between the Uppsala, Sörmland, Västmanland, Värmland and Örebro county councils in Sweden</td>
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<td>COPD</td>
<td>Chronic obstructive pulmonary disease</td>
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<td>DM</td>
<td>Diabetes mellitus</td>
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<td>EQ-5D</td>
<td>The EuroQol five-dimension questionnaire</td>
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<td>ERS</td>
<td>European Respiratory Society</td>
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<td>FET</td>
<td>Forced Expiratory Time</td>
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<td>FEV&lt;sub&gt;1&lt;/sub&gt;</td>
<td>Forced Expiratory Volume in one second</td>
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<td>FEV&lt;sub&gt;6&lt;/sub&gt;</td>
<td>Forced Expiratory Volume in six seconds</td>
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<td>FVC</td>
<td>Forced Vital Capacity</td>
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<td>GOLD</td>
<td>The Global Initiative for Chronic Obstructive Lung Disease</td>
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<td>HRQoL</td>
<td>Health related quality of life</td>
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<td>MRC</td>
<td>Medical Research Council</td>
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<td>PA</td>
<td>Physical activity</td>
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<td>PR</td>
<td>Pulmonary rehabilitation</td>
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<td>RA</td>
<td>Rheumatoid arthritis</td>
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<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
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<td>VC</td>
<td>Vital Capacity</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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Introduction

Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality. It is often related to tobacco smoking as a major risk factor.

COPD is increasing worldwide due to continued exposure to risk factors and the changing age structure of the population in developing countries. COPD has been more recognized among the general population during the last decade [1]. This has resulted in awareness of the disease and possibilities for people contracting the disease to seek medical advice.

COPD provides opportunities for prevention, as it is often associated not only with smoking, but physical inactivity and poor diet as well. The phrase “preventable and treatable” is used in the ATS/ERS (American Thoracic Society / European Respiratory Society) position paper from 2004 [2] and in the GOLD report, (Global Strategy for the Diagnosis, Management, and Prevention of COPD, www.goldcopd.org) [3]. This supports the need to present a positive outlook for patients and encourage the health care community to take a more active role in developing prevention and treatment programs [4]. The importance of early detection has been previously stressed [5] and becomes even more important when possibilities of prevention, intervention and treatment can be considered.

Definition of COPD

The current GOLD guidelines (update 2009) have a working definition of COPD [3]:

“Chronic Obstructive Pulmonary Disease (COPD) is a preventable and treatable disease with some significant extrapulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterized by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious particles or gases.”

Although tobacco smoking is the major risk factor for COPD in developed countries, other risk factors are important globally. In developing countries many people are exposed to smoke from biomass fuels. An estimated 25-45% of patients with COPD have never smoked and the burden of non-smoking COPD is therefore much higher than previously believed [6].
The GOLD guidelines [3], do not include the terms emphysema and chronic bronchitis in the definition of COPD, though small airway disease (obstructive bronchiolitis) and parenchymal destruction (emphysema) are described as contributors to the chronic airflow limitation characteristic of COPD [3].

History of COPD

The term COPD is believed to have been used for the first time in a publication from 1964, where the expression in the title was “Chronic Obstructive Bronchopulmonary Disease” [7]. During the following decades the term COPD became common among health professionals and during the last decade in the general population.

The previous definitions of COPD have stressed the terms “emphysema” and “chronic bronchitis”, not included in the current definition of the GOLD guidelines [3]. Emphysema was originally described in the beginning of the 19th century by among others, Laennec, the inventor of the stethoscope. Chronic bronchitis also has its origin from the same period. In 1959 obstructive lung diseases were more strictly defined in the CIBA Guest Symposium [8]. Emphysema was defined as “a condition of the lung characterized by increase beyond the normal of air spaces, distal to the terminal bronchiole either from dilatation or from destruction of their walls”. In the same report: “Chronic bronchitis refers to the condition of subjects with chronic or recurrent excessive mucous secretion in the bronchial tree” [8]. Together, “chronic bronchitis and emphysema” (CBE), has been the expression used that comes closest to the “new” term COPD. The term COPD has been used during the last four decades and have gradually become more standardised. In 1987 ATS defined COPD as “emphysema, peripheral airways disease and chronic bronchitis” [9]. Subjects with COPD had one or more of these conditions. It was stated that the main components of COPD are chronic bronchitis and emphysema [10] and that “COPD is the well-established term for obstructive lung function impairment most often due to chronic bronchitis and/or emphysema” [11].

Prevalence

Prevalence can be defined as the proportion or number of people with a disease or condition in a given population at a specific time. Prevalence of COPD can vary depending on many factors e.g. diagnostic criteria, age and survey methods.

In a systematic review Halbert et al [12] estimated the prevalence of physiologically defined COPD in adults ≥40 yrs to be 9-10%. In northern
Sweden, the OLIN studies reported data on distribution of disease severity according to GOLD criteria; 57% mild, 37% moderate, 5% severe and 1% very severe disease [13]. This information of a large proportion having mild/moderate disease may be important for the individual when getting a diagnosis of COPD, with possibilities of having a positive future outlook.

Concerning survey methods, patient-reported diagnosis results in the lowest prevalence numbers of COPD, and appears to underestimate disease prevalence [12].

Further increases in the prevalence and mortality of COPD can be expected over the coming decades [3, 14].

Airflow limitation in COPD

Chronic airflow limitation is a characteristic of COPD and is caused by peripheral airway disease and destruction of lung parenchyma. Inflammatory processes cause structural changes and decrease in elastic recoil. This contributes to dynamic compression and thereby a difference in volume between performing a slow and forced vital capacity manoeuvre [15].

The latest criteria for diagnosis and staging of COPD tend to be rather congruent though there is an ongoing debate regarding some parts of the criteria, e.g. the forced expiratory volume in one second (FEV$_1$) / vital capacity (VC) or FEV$_1$ / forced vital capacity (FVC) ratio. This is illustrated in Table 1 by the differences between the Swedish definition, where the highest FVC or VC is chosen in the denominator, and the ATS/ERS and GOLD definitions. In addition the Swedish guidelines have adopted a two-level age adjustment. It is known that, when using spirometry, a fixed post-bronchodilator FEV$_1$/FVC ratio less than 0.70 risks overdiagnosing elderly individuals and underdiagnosing younger adults [3, 16, 17].
Table 1. Spirometric definition of COPD according to ATS/ERS [2], GOLD [3] and Swedish national guidelines [18]. All values are post-bronchodilator.

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<td>Definition</td>
<td>FEV₁/FVC ≤ 0.7</td>
<td>FEV₁/FVC ≤ 0.70</td>
<td>FEV₁/(FVC or VC) &lt; 0.70 or &lt; 0.65 §/</td>
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<td>At risk</td>
<td>FEV₁/FVC &gt; 0.7 */</td>
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Stages according to FEV₁ % of predicted value

| I Mild | FEV₁ ≥ 80 | FEV₁ ≥ 80 | FEV₁ ≥ 80 | 1 |
| II Moderate | FEV₁ 50-80 | 50 ≤ FEV₁ < 80 | FEV₁ 50-79 | 2 |
| III Severe | FEV₁ 30-50 | 30 ≤ FEV₁ < 50 | FEV₁ 30-49 | 3 |
| IV Very severe | FEV₁ < 30 | FEV₁ < 30 */ | FEV₁ < 30 */ | 4 |

FEV₁: forced expiratory volume in one second, FVC: forced vital capacity, VC: vital capacity, */ Patients who smoke, are exposed to pollutants and have a cough, sputum or dyspnoea, °/ FVC or VC whichever is highest, §/ <0.70, but if older than 65 years; <0.65, or age- and gender-adjusted lower limit, */ or FEV₁ < 50% predicted plus chronic respiratory failure / negative prognostic factors.

Confirmation with spirometry

Spirometry is essential in confirming the diagnosis of COPD. Primary care has a central role in diagnosis and management of respiratory diseases and spirometry is needed to support clinical decision making as it is the only way to document airflow obstruction [19]. There is a focus and an ongoing debate on primary care spirometry and expectations that spirometry can be applied as part of routine general care rather than just in special institutions [20]. As early as 2000 “office spirometry” was recommended in a consensus statement from the National Lung Health Education Program in the US to make spirometry use more widespread [21].

According to guidelines, spirometry should be performed after administration of an adequate dose of an inhaled bronchodilator [3]. Post-bronchodilator FEV₁ measurements are also essential for the assessment of severity of COPD. It is reported that the reversibility in patients with COPD was substantial and the prevalence of COPD was 27% lower than when prevalence was defined without bronchodilatation [22]. Prebronchodilator
measurements in epidemiological studies might misclassify COPD, especially in mild stages and can be undiagnosed asthma [17, 23].

The use of FEV$_6$ (forced expiratory volume in six seconds) instead of FVC as denominator in the FEV$_1$/FVC ratio is discussed [24-27]. An advantage using FEV$_6$ can be that the end of an expiratory manoeuvre is more explicitly defined and easier to achieve [28]. There are as yet no reference values available in Europe for FEV$_6$.

**Spirometry in clinical practice in Sweden**

The role of spirometry in primary care in the detection of COPD was investigated in the years 1992/1997 in southern Sweden while an increasing number of primary health care centres were equipped with spirometers [29]. This study also supports the fact that COPD is greatly underdiagnosed.

In 2000, 77% of primary health care centres had access to a spirometer in a region in mid-Sweden, but more frequent use of spirometers was recommended [30].

Thorn *et al* (2008) [31] reported that 95% of primary care centres in a region in western Sweden had access to spirometry equipment and more than 90% used it at least several times a week.

A recently published study describes COPD health care structure and process in Swedish clinical practice nationwide [32]. In this study spirometers were available in 99% of participating primary care centres and in all hospital based outpatient clinics. Spirometry had been performed during the last two years in 52% of patients with COPD in primary care and in 89% of patients in hospital based outpatient clinics.

**COPD in the general population**

COPD has been described as a poorly recognized and often misunderstood condition. People in general have had little knowledge about the disease [33-35], but during the recent decade COPD has become a more recognized disease entity. Thus, it is now possible to identify persons with self-reported COPD in the adult population and inquire about their health status and quality of life.

In the “Confronting COPD International Survey”, performed in the year 2000, it was summarized that subjects with COPD may be both underdiagnosed and undertreated. It was also reported that subjects with COPD in the population appeared to suffer from relatively severe dyspnoea and disability despite often regarding their disease as mild to moderate [33]. It was recommended to raise public awareness of COPD and to improve implementation of recommended diagnostic and therapeutic modalities.
Consequences of COPD for the individual

*Dyspnoea* is a common symptom in subjects with COPD, related to the airflow limitation and dynamic hyperinflation, often in response to increased ventilation during physical activity [36]. To avoid dyspnoea, subjects with COPD tend to avoid physical exertion and adapt a more sedentary lifestyle than healthy subjects [37]. This can lead into a vicious circle with decreased physical capacity, more dyspnoea during activity, activity avoidance, decreased physical fitness and muscle mass, dyspnoea during light activities of daily living, reduced health related quality of life (HRQoL), depression, and social isolation.

Other common symptoms as *cough* and *sputum production* may precede the development of airflow limitation by many years [3].

Furthermore, the *systemic effects*, not affecting the lungs, are important to recognize. These have been categorized by Agusti *et al* [38] as: systemic inflammation, nutritional abnormalities and weight loss, skeletal muscle dysfunction and other potential systemic effects as cardiovascular, nervous system and osteoskeletal effects.

Early detection

Early detection of COPD is important to prevent disease progress. Van den Boom *et al* could in 1998 confirm that underdiagnosis of COPD and asthma was a substantial problem and that 74% of all subjects with signs of COPD or asthma never consulted their general practitioner for these complaints [39]. Miravitlles *et al* recently stated that individuals with respiratory symptoms do not request medical attention and do not attempt to quit smoking. There is a lack of knowledge about COPD and increase in the use of spirometry for early detection is advocated [34]. Kornmann *et al* found that half the patients presenting with COPD were in GOLD stages 0-1 and therefore eligible for behavioural intervention and prevention [40]. Lindberg *et al* reported a large underdiagnosis of COPD and described it in two steps; in society, where subjects were unaware of the disease despite experiencing respiratory symptoms and secondly in health care as subjects seeking medical advice only rarely were diagnosed [41]. Identifying COPD early will increase the possibility to support smoking cessation and to prevent decline in lung function [42].

Making a diagnosis of COPD is often delayed, often because of adaptation to symptoms by the patient [42]. Believing that the “smoker’s cough” is normal can cause a patient’s delay [43] and in the next step a doctor’s delay can be present e.g. by not performing diagnostic spirometry [34]. In addition the diagnosis may not have been communicated to the patient, as there can be reluctance on the part of the physicians in primary care to protect patients...
against psychological impact because of pre-existing depression and anxiety [44].

**Multidimensional grading system**

Spirometry is mandatory for diagnosing COPD and classification of severity. However it is important to emphasize that spirometry is not describing functional limitations or perceived quality of life. Exercise capacity, health related quality of life and participation in activities of daily living are often not proportional to lung function impairment [45]. Suggestions of an index “BODE-index” [46], involving body mass index (BMI), obstruction (FEV₁ percent predicted), dyspnoea (MRC-scale) and exercise (6MWD) illustrates the need for not just looking at spirometric values in interpreting COPD. This is underlined by recognizing that COPD involves several systemic features with major impact on function for the individual patient, but also on survival and comorbid diseases [3]. Future research is needed to evaluate components of importance for the patient with COPD.

**Comorbidity**

Patients with COPD often have other diseases making it important to have a patient-oriented approach taking into account that co-existing components of the chronic disease can contribute to the patient’s symptoms. Extrapulmonary effects of COPD such as weight loss, nutritional abnormalities and skeletal muscle dysfunction are documented and COPD is associated with many comorbidities, such as cardiovascular, bone, and other smoking related diseases already present at the time of diagnosis [47]. Comorbidity is an important predictor of HRQoL and asking about e.g. sleeping problems and other problems in daily functioning and well-being is essential [48]. Furthermore, anxiety and depression as well as fatigue are problems associated with COPD [49-54].

It has been found that depressed patients with COPD had poor exercise performance and poor health status, with associations to the BODE index [46], but no associations with the level of FEV₁ [55]. This underlines the multisystem nature of COPD and the need for early identification and management of depression in patients with COPD.
Management of COPD

Prevention - Reduce risk factors

Reduction of exposure to tobacco smoke, occupational dusts and chemicals, and air pollutants are important to prevent the onset and progression of COPD. Smoking cessation is the single most effective intervention to reduce the risk of developing COPD and stop its progression [3, 10].

Manage stable COPD

The role of educational activities has been poorly studied although generally regarded as essential in the care of chronic diseases. Patient education alone has not been shown to have an effect on exercise performance or lung function, but can play a role in the ability to cope with illness [56]. Self-management education had no effect on hospital admissions, emergency rooms visits, days lost from work, or lung function according to a Cochrane review [57], while Bourbeau et al [58] reported reduction of hospitalisations and emergency room visits after self-management intervention.

Pharmacologic treatment

Pharmacotherapy is used mainly to prevent and control symptoms, reduce the severity of exacerbations, improve health status, and improve exercise tolerance [3]. Possibilities of decreasing the rate of decline of lung function are interesting future aspects.

Non-pharmacologic treatment

Rehabilitation

The applicability of pulmonary rehabilitation (PR) has been extended as a result of research and it is stated that PR is of value for all patients in which respiratory symptoms are associated with diminished functional capacity or reduced health related quality of life [51]. It is proposed that PR should be a part of the clinical management of all patients with COPD addressing their functional and/or psychological deficits.

Troosters et al states that PR by individualized rehabilitation programs can have candidates at both ends of the disease spectrum in COPD [45]. As an example, Berry et al [59], reports that COPD patients in all stages improved in exercise tolerance, dyspnoea and fatigue after a 12-week exercise program.

Behaviour modification as a part of self-management can include smoking cessation, regular exercise, nutritional intervention and sleep habits. Skills of self-management must be integrated in the patient’s everyday life and simply teaching these skills is not enough to bring about change in beh-
haviour. Self-efficacy plays a part in determining which activities or situations an individual will perform or avoid [60].

Manage exacerbations

An exacerbation is characterized by increased dyspnoea, cough and/or sputum production and affects the quality of life and prognosis of patients with COPD. COPD exacerbations are an important part of the morbidity, mortality and progression of the disease [61]. Treatment with bronchodilators, glucocorticosteroids and antibiotics as well as hospital management with oxygen therapy and ventilatory support may be indicated [3]. In a recent Cochrane review it was suggested that PR is a highly effective and safe intervention that reduces hospital admissions and mortality and improves HRQoL in patients with COPD after suffering an exacerbation [62]. Thus, PR should also be emphasised in connection with exacerbations.

Management of COPD in different settings

The current update of GOLD has a chapter about translating guideline recommendations to the context of (primary) care [3]. Key points of this chapter are:

- There is considerable evidence that management of COPD generally is not in accordance with current guidelines. Better dissemination of guidelines and their effective implementation in a variety of health care settings is urgently required.
- In many countries, primary care practitioners treat the vast majority of patients with COPD and may be actively involved in public health campaigns and in bringing messages about reducing exposure to risk factors to both patients and the public.
- Spirometric confirmation is a key component of the diagnosis of COPD and primary care practitioners should have access to high-quality spirometry.
- Older patients frequently have multiple chronic health conditions. Comorbidities can magnify the impact of COPD on a patient’s health status, and can complicate the management of COPD.

COPD; a chronic disease

Chronic diseases in general account for a large amount of burden of disease and as COPD has now become more recognized among the general population it is possible to investigate the impact of COPD compared to other chronic diseases in the population. By investigating impact of disease, health
status and prevalence of risk factors a better understanding of influence on the individual can be achieved. As many chronic diseases are possible to prevent it is important to shed light on these possibilities. This has been noticed globally by the WHO publication *Preventing Chronic Diseases: A Vital Investment* [63], where unhealthy diet, physical inactivity and tobacco use are pointed out as examples of common, modifiable risk factors underlying major chronic diseases.

**Quality of life**

**Definitions**

The concept of quality of life is multidimensional and complex, and no universally accepted definition exists. *Quality of life* is often described as a person’s physical and material well-being or satisfaction with life, as well as relations with other people, personal development and fulfilment, and is related to health; health related quality of life (HRQoL) [64]. HRQoL has been defined as “the degree to which a patient’s health status affects their self-determined evaluation of satisfaction, or quality of life” [65]. Ferrans et al [66] describe a model for HRQoL as a sequence of components which can be influenced by characteristics of both the individual and the environment. The components of the model are 1) biological function, 2) symptoms, 3) functional status, 4) general health perceptions and 5) overall quality of life. These components represent five types of measures of patient outcomes. In this thesis health status is assessed in the population surveys by answers to the question “How do you rate your general health status?” rated on a Likert item. This component of HRQoL; “general health perception”, is characterised by integrating all components that come earlier in the “Ferrans model” and are subjective in nature [66].

*Health status* can be defined as the impact of health on a person’s ability to perform and derive fulfilment from the activities of daily life. In addition a patient’s self-reported health status thus includes HRQoL and functional status [67]. General health status in COPD decreases with increasing disease severity [68] and age [69].

According to the framework of Leidy (1994), *functional status* can be divided into the dimensions: functional capacity, functional performance, functional capacity utilization and functional reserve [70]. Consistent with these dimensions *functional capacity* can be a person’s maximal ability in strength and endurance. *Functional performance* refers to activities a person performs on a day-to-day basis and could be assessed by the level of physical activity and energy expended or as self-reported activities. Thus, functional capacity and functional performance are related to *physical activity*
which has been a term frequently used in connection with health promotion and treatment of diseases in several publications [71-74].

Physical activity

Definition

*Physical activity* is defined as any bodily movement produced by skeletal muscles that result in energy expenditure beyond resting expenditure [71].

Physical activity in daily life

In prospective observational studies it has been shown that disease outcomes are inversely related to regular physical activity in e.g. cardiovascular disease, thromboembolic stroke, hypertension, type 2 diabetes mellitus, osteoporosis, obesity, colon cancer, breast cancer, anxiety and depression [74].

The recommendation to promote and maintain health is that all healthy adults aged 18 to 65 need moderate intensity, aerobic physical activity for a minimum of 30 minutes, five days every week or vigorous intensity aerobic activity for a minimum of 20 minutes on three days weekly. Moderate intensity aerobic activity is generally equivalent to a brisk walk and noticeably accelerates the heart rate [74].

There is also strong evidence that physical activity should be one of the highest priorities for preventing and treating disease and disablement in older adults [75]. In addition to the mentioned above benefits of physical activity in adults, physical activity in older adults also can be effective therapy for many chronic diseases; coronary heart disease, peripheral vascular disease, elevated cholesterol, osteoarthritis, claudication and COPD [75].

In COPD patients Pitta *et al* investigated physical activities in daily life compared with healthy age-matched individuals. They found that most patients with COPD spent less time walking and standing and more time sitting and lying when compared with healthy subjects. Walking speed was significantly slower than the walking speed of healthy subjects [37].

The historical hypothesis of whether muscle weakness as a consequence of systemic inflammation is correct has been discussed. One reason is that muscle weakness of the quadriceps usually precedes cachexia and that muscle weakness in COPD has a regional distribution with sparing of abdominal muscles and upper limb muscles [76]. An alternative hypothesis could therefore be, that reduced physical activity is an early feature of COPD leading to muscle atrophy [76]. In a recent study, Watz *et al* [77], investigated physical activity in patients with COPD and found that physical activity was already reduced at GOLD stage II [3] or BODE score 1 [46], suggesting that patients spontaneously chose to reduce their activity rather than be restricted by pul-
monary limitation, which implies a behavioural component possible to influence.

Pelkonen et al reported in a longitudinal study of middle-aged men followed up to 25 years, that higher physical activity was related to a slower decline in lung function. Physical activity appeared to be beneficial in both smokers and non-smokers [78].

In a population-based survey in Canada, where subjects reporting having asthma were investigated [79], greater physical activity was associated with better overall health. In addition there was a gradient from being inactive to greater activity levels parallel with better reported health.

General remarks

COPD is often diagnosed late. It is a disease which often has its etiology decades before the onset of symptoms [2]. Investigating the perceptions and perspectives of the individual in the stage of receiving a diagnosis of COPD can provide a better understanding of the process underlying detection of the disease.

COPD is a chronic disease, common in the general population, and as a consequence a public health problem. Analysing data from public health surveys can provide information on the impact of chronic diseases on health status, quality of life, physical activity, and factors associated with these outcomes.

As COPD is managed in different settings it is interesting to look into the management of the disease in current clinical practice. The Swedish National Board of Health and Welfare produced guidelines for asthma and COPD in 2004. “Praxisstudien” intends to compare these guidelines to the actually performed care in primary and secondary care during the years 2000-2003. In “Praxisstudien” data in medical records on patients can be analysed in connection with a new diagnosis of COPD.
Aims

The overall aim of this thesis was to describe subjects with COPD from different perspectives. Focus was on patients at the time of diagnosis, impact of the disease in comparison to other chronic diseases, factors associated with good health and quality of life, and diagnostic spirometry in clinical practice.

Specific aims were:

- to gain an understanding of patients’ perspectives and perceptions of their disease at the time of COPD diagnosis (I)
- to describe and compare the level of physical activity, health-related quality of life, and psychological health in subjects with COPD, rheumatoid arthritis (RA), and diabetes mellitus (DM), and in healthy subjects in a population-based study (II)
- to investigate factors associated with good self-rated health and quality of life in subjects with self-reported COPD in the population (III)
- to investigate to what extent documented spirometry test results confirmed the diagnosis of COPD in primary and secondary care in mid-Sweden during the years 2000-2003 (IV)
- to assess the quality of spirometry tests performed in connection with a new diagnosis of COPD (IV)
Ethical approval

Patients in paper I gave their informed consent to participate in the study and the regional ethical committee in Örebro approved the study.

Paper II and III were population studies with de-identified personal data and according to the Swedish laws of medical research ethics ethical approval was not required.

Paper IV was approved by the Research Ethics Board at Uppsala University.
Subjects and methods

This thesis consists of four papers (Table 2).

Paper I is based on a qualitative study of patients with COPD in primary care in the county of Värmland, Sweden.

The two following papers are cross-sectional studies based on general population surveys, “Liv och hälsa”, in the CDUST-region in mid-Sweden (the counties of Uppsala, Sörmland, Västmanland, Värmland and Örebro) in the years 2004 (paper II), and 2004 and 2008 (paper III).

Paper IV is a cross-sectional study based on a survey in the Uppsala-Örebro region (the counties of Dalarna and Gävleborg in addition to the CDUST counties) “Praxisstudien”. A questionnaire was sent to patients with COPD in primary and secondary care in 2005 and, after permission, their medical records from 2000-2003 (four years) were examined.

Data collection and analysis

In paper I, patients in primary care (n=10), 6 women and 4 men, were interviewed and data were analysed according to the qualitative method grounded theory [80]. The patients were newly (within the previous year) diagnosed with COPD or suspected COPD. Included patients had an airflow limitation with a FEV1/FVC ratio below 0.70 according to GOLD [3] and had a minimum tobacco consumption of 10 pack years (one pack year is equal to smoking 20 cigarettes per day for one year). In addition all patients fulfilled the gender and age adjusted criteria for obstruction of the Swedish national guidelines [18].

The patients were recruited by their physician; primary care physicians in the central part of Värmland were informed about the inclusion criteria and purpose of the study. The sampling of patients was purposive with the intention to cover a broad spectrum of characteristics and information. In grounded theory, data collection (in this study; interview) and analysis is a parallel process, where experiences from previous interviews are brought forward to subsequent interviews.
Table 2. Baseline characteristics for the studies in the thesis.

<table>
<thead>
<tr>
<th>Setting</th>
<th>Paper I</th>
<th>Paper II</th>
<th>Paper III</th>
<th>Paper IV</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Primary care</td>
<td>Population based</td>
<td>Population based</td>
<td>Primary and</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>secondary care</td>
</tr>
<tr>
<td>Age range (years)</td>
<td>48-76</td>
<td>40-84</td>
<td>40-84</td>
<td>34-75</td>
</tr>
<tr>
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<td>31,606</td>
<td>31,606</td>
<td>1,114</td>
</tr>
<tr>
<td>Participants</td>
<td>10</td>
<td>10,755</td>
<td>664</td>
<td>533</td>
</tr>
<tr>
<td>Sex (females, % of</td>
<td>60</td>
<td>44</td>
<td>44</td>
<td>58</td>
</tr>
<tr>
<td>subjects with COPD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnoses</td>
<td>COPD</td>
<td>COPD, DM, RA</td>
<td>COPD</td>
<td>COPD</td>
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<td>Qualitative/</td>
<td>Observational/</td>
<td>Observational/</td>
<td>Observational/</td>
</tr>
<tr>
<td></td>
<td>descriptive</td>
<td>Cross-sectional</td>
<td>Cross-sectional</td>
<td>Cross-sectional</td>
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<tr>
<td>Data collection</td>
<td>Interview,</td>
<td>Questionnaire</td>
<td>Questionnaire</td>
<td>Medical records,</td>
</tr>
<tr>
<td></td>
<td>grounded</td>
<td></td>
<td></td>
<td>questionnaire</td>
</tr>
<tr>
<td></td>
<td>theory</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data analysis</td>
<td>Grounded theory</td>
<td>Descriptive,</td>
<td>Descriptive,</td>
<td>Descriptive,</td>
</tr>
<tr>
<td></td>
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<td>inference,</td>
<td>inference,</td>
<td>inference</td>
</tr>
<tr>
<td></td>
<td></td>
<td>regression</td>
<td>regression</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>analysis</td>
<td>analysis</td>
<td></td>
</tr>
</tbody>
</table>

n/a: not applicable, COPD: Chronic obstructive pulmonary disease, DM: Diabetes mellitus, RA: Rheumatoid arthritis.

The question “Can you tell me something about your life in connection with your lung trouble?” was the opening of the interview. The patients were free to raise the issues that were important to them. The interviews were recorded and transcribed verbatim and lasted between 39 and 63 minutes and the processing of the data was done in the Open Code program [81]. At first, the coding was open, analysing every sentence to generate substantive codes, which were then grouped into seven subcategories and five main categories. Comparisons were constantly made and memos written during the process. Thereafter selective coding was done, focusing on a core category central to the data and related to all categories. The final theoretical coding formed a structure which integrated the categories for the purpose of building a model.

In paper II and III, data from the cross-sectional, population surveys “Liv och hälsa”, was analysed. Data in the main survey was collected by postal survey questionnaires (21 pages), to Swedish women and men aged 18-84 years. The area investigated covered 55 municipalities in five counties in...
mid-Sweden with approximately one million inhabitants. The sampling was random after stratification for gender, age group, county, and municipality.

In paper II, the survey from 2004 was analysed with focus on chronic diseases, where subjects 40-84 years old (n=31,606), with COPD (n=526), rheumatoid arthritis (n=1,120), diabetes mellitus (n=2,149) and healthy subjects (n=6,960) were compared regarding physical activity, psychological health, and quality of life.

In paper III the surveys from 2004 and 2008 were analysed regarding subjects (40-84 years old) with self-reported COPD (n=1,475).

**General health status** was assessed by the answer to the question “How do you rate your general health status?” with the alternatives; very good/good/neither good nor poor/poor/very poor [82].

Psychological health was assessed by **The General Health Questionnaire (GHQ)**, a self-reported questionnaire designed to identify psychological disorders, mainly within the anxiety/depression spectrum [83]. In paper II and III the 12-item version (GHQ12) was used [84]. Scores were calculated from dichotomizing the 12 items (0=equal or better than usual, 1=worse than usual), and psychological distress was defined as present when the total score was 3 or higher.

Quality of life was assessed by the standardised measure developed by the EuroQoL Group [85]. **The EuroQol five-dimension questionnaire (EQ-5D)**, consists of the five dimensions; mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, each of which offered three possible responses; no problems/some or moderate problems/extreme problems (Figure 1). The index of EQ-5D was computed according to Burström et al [86], (1=full health, 0= death).

**Physical activity** in leisure time the last 12 months was estimated on a four-category scale with origin from Saltin et al (1968) [88], commonly used in public health surveys. The scale indicated: (A) sedentary (mostly sitting or low activity <2 hours a week); (B) moderate exercise (low activity >2 hours a week); (C) moderate regular exercise (high activity >30 minutes, 1-2 times a week); (D) regular exercise and training (high activity >30 minutes ≥3 times a week) [89]. This variable was dichotomized in low activity level (A and B) and high activity level (C and D) corresponding to the recommended minimum level by Nelson et al [75].
EQ-5D descriptive system

| Mobility | I have no problems walking about
| I have some problems in walking about
| I am confined to bed
| Self-Care | I have no problems with self-care
| I have some problems washing or dressing myself
| I am unable to wash or dress myself
| Usual Activities (e.g. work, study, housework, family or leisure activities) | I have no problems with performing my usual activities
| I have some problems with performing my usual activities
| I am unable to perform my usual activities
| Pain/Discomfort | I have no pain or discomfort
| I have moderate pain or discomfort
| I have extreme pain or discomfort
| Anxiety/Depression | I am not anxious or depressed
| I am moderately anxious or depressed
| I am extremely anxious or depressed

Figure 1. The EQ-5D descriptive system [87].

In paper II additional questions on anxiety and worry, fatigue, sleeping problems, depression and “personal opinion on your future” were assessed.

In paper III, comorbidity factors; cardiovascular disease, hypertension, asthma, depression and chronic fatigue syndrome were added.

In paper IV a survey was sent to randomly selected patients with COPD attending 56 primary health care centres and 14 outpatients pulmonary departments in hospitals (secondary care). Data from 778 patients in primary care and 336 patients in secondary care were possible to evaluate. From these 1,114 patients with COPD, all those with a specified date for new diagnosis of COPD during the study period were identified (n=533).

Data from medical records from 2000 to 2003 inclusive were abstracted and analysed by two research nurses. Data on current smoking habits were obtained via a questionnaire sent to the patients in 2005. Questions about smoking habits were “Do you smoke?” with the alternatives: No, I have never smoked regularly/No, I have stopped smoking/Yes, I smoke occasionally/Yes, I smoke daily and an open question: “If you smoke or earlier have smoked daily – How many years have you smoked daily?”

Diagnostic spirometry was defined as spirometry performed during the interval starting six months prior to diagnosis of COPD and ending six months
after the date of diagnosis. Spirometry data used were any pre- or post-bronchodilator values from either FEV₁, FEV₁ percent predicted or FEV₁/VC ratio in spirometry reports or in medical records. Predicted values were according to, or transformed to, European Community for Steel and Coal (ECSC) reference values [90]. Post-bronchodilator FEV₁/VC ratios were obtained from records or calculated, where the highest VC value from a slow vital capacity test (SVC) or a forced manoeuvre, forced vital capacity (FVC) was used according to American Thoracic Society (ATS)/European Respiratory Society (ERS) criteria [91]. Spirometry devices used were pneumotachographs, ultrasound sensors or turbine transducers with computer software from several manufacturers.

Available flow-volume and volume-time curves were analysed visually. The best curve – the one with the largest sum of FEV₁ and FVC was consequently used for analysis. According to guidelines current during the study period (ATS 1995) [92], acceptability criteria were: having good starts, free from artefacts, and showing satisfactory exhalation. Our analysis included visual inspection of the flow-volume curves, which were scored “acceptable” or “not acceptable”: start of test (steep upslope), shape of peak (sharp) and artefacts (no artefacts during the first second). End-of-tests were assessed in both the flow-volume curves (no cut-off) and volume-time curves (acceptable plateau). Forced expiratory time (FET) (limit ≥ 6 seconds) was estimated from the volume-time curves.

Statistical methods

In paper I no quantitative analysis was performed as the study was according to qualitative method.

In paper II the Chi-square test was used to analyse the relationship between categorical variables. Analysis of variance (ANOVA) was used for analysis of continuous data. Binary logistic regression was performed to calculate odds ratios adjusted for background data; sex, age, smoking, BMI, educational level, employment status, economic problems and living alone. COPD was compared to RA, diabetes mellitus, and healthy subjects with 95% confidence intervals. All statistical tests were two-sided and comparisons with a probability of error <5% were considered significant. The statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS) 15.0 statistical software.

In paper III regression models were used to analyse the association between health measures (general health status, GHQ12 index, and a categorized EQ-5D index using 10 equally large subintervals of the unit interval) and a predefined set of explanatory variables. Three models were analysed for each measure: Level 1 - a base model having age and sex as explanatory variables, Level 2 - base model and additional factors (BMI, economic prob-
lems, alcohol use, educational level, social support, smoking status and physical activity), and Level 3 - base model, additional factors and comorbidity (cardiovascular disease, hypertension, asthma, depression and chronic fatigue syndrome).

Level 1 variables were retained in all models. At Levels 2 and 3 only those variables having significant coefficients were retained (except for smoking habits which remained regardless of strength of association).

The analysis at Level 2 consisted of an inclusion step and an exclusion step. In the inclusion step each of the additional factors were analysed together with base factors and included if they showed significant effects. In the next step analyses of all included additional factors were performed and those not showing significant effects were removed (exclusion step). The reduced model was then reanalysed.

At Level 3 all comorbidity variables were added simultaneously, and those not significant were excluded and the analysis rerun. At the inclusion step the more liberal 0.10 significance level was used, and in the exclusion step the usual 0.05 level was used.

Generalized additive models with logistic link for the general health status and GHQ12 were used. EQ-5D was analysed using an ordinal regression model. All associations were measured as odds ratios.

Regression analyses were carried out using multivariate regression splines [93] with ordinal regression in Stata/IC 10 (Stata Corp LP, College Station, Texas).

In paper IV, \( t \) tests were used for analysing continuous data. For non-parametric data chi-square tests were used with Yates' corrected chi-square (continuity correction) computed for all \( 2 \times 2 \) tables. Two-sided \( p \) values of \( <0.05 \) were considered statistically significant. The data were analysed using the statistical software SPSS 15.0.
Results

Paper I

Patients’ characteristics are presented in Table 3. The results are presented with the aid of a model (Figure 2) constructed from the data analysis.

In addition to the core category **Consequences of smoking**, five main categories **Shame**, **Appearance of symptoms**, **Adaptation**, **Reflection** and **Action** were defined. The core category, main categories and seven subcategories interacted and described a process.

The patients had started smoking without knowing or thinking about future consequences. Smoking continued for years before the **Appearance of symptoms** emerged. One indicator of disease progression was **Restrictions in physical activity**. **Adaptation** to the disease could appear parallel to appearance of symptoms. **Reflection** on smoking as a risk factor for getting a disease, including **Reflection on stopping smoking** and **Reflection on seeking advice**, was part of the process. The main category, **Action**, presented active steps to seek medical advice or otherwise deal with the disease. Acute symptoms promoted seeking care: Take action. **Getting a diagnosis** was important to the patients, but also filled them with fear of e.g. cancer.

**Shame**

**Shame** proved to be a main category that interacted with most others and also hindered people from taking action. Shame was evident throughout the interviews and this category emerged from the entire process during the analysis. Although not always explicit, there were statements that referred to the disease as self-inflicted and caused by smoking. Shame was undoubtedly an obstacle to seeking advice.

**Appearance of symptoms**

Symptoms could be present, but were initially not recognized by the patient as signs of disease.

**Appearance of symptoms** was an indicator of disease progression. First symptoms occurred intermittently, and often in combination with upper-respiratory tract infections. Symptoms as coughing, wheezing, rattling, secretions and moments of difficulty in breathing could appear.
Table 3. Patients’ characteristics (Paper I).

<table>
<thead>
<tr>
<th>Patient</th>
<th>Sex</th>
<th>Age (yrs)</th>
<th>FEV% (FEV₁/FVC) (%)</th>
<th>FEV₁ (L)</th>
<th>FEV₁ %pred</th>
<th>GOLD stage</th>
<th>Current smoker</th>
<th>Smoking; pack years</th>
<th>Start of symptoms (years before interview)</th>
<th>Spirometry performed before interview</th>
<th>Diagnosis of COPD (months before interview)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>48</td>
<td>37</td>
<td>1.7</td>
<td>64</td>
<td>II</td>
<td>N</td>
<td>15</td>
<td>3</td>
<td>Y</td>
<td>&lt;1</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>69</td>
<td>39</td>
<td>1.2</td>
<td>39</td>
<td>III</td>
<td>Y</td>
<td>37</td>
<td>2</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>58</td>
<td>50</td>
<td>1.5</td>
<td>58</td>
<td>II</td>
<td>Y</td>
<td>33</td>
<td>10</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>62</td>
<td>52</td>
<td>1.7</td>
<td>70</td>
<td>II</td>
<td>Y</td>
<td>23</td>
<td>10</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>62</td>
<td>66</td>
<td>3.0</td>
<td>87</td>
<td>I</td>
<td>N</td>
<td>42</td>
<td>1.5</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>71</td>
<td>64</td>
<td>1.1</td>
<td>56</td>
<td>II</td>
<td>N</td>
<td>12</td>
<td>&lt;1</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>64</td>
<td>58</td>
<td>2.8</td>
<td>86</td>
<td>I</td>
<td>N</td>
<td>22</td>
<td>20</td>
<td>Y</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>F</td>
<td>64</td>
<td>64</td>
<td>2.0</td>
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<td>35</td>
<td>&lt;1</td>
<td>Y</td>
<td>1</td>
</tr>
<tr>
<td>9</td>
<td>F</td>
<td>57</td>
<td>67</td>
<td>2.1</td>
<td>84</td>
<td>I</td>
<td>Y</td>
<td>35</td>
<td>15</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>10</td>
<td>M</td>
<td>76</td>
<td>56</td>
<td>2.3</td>
<td>86</td>
<td>I</td>
<td>N</td>
<td>60</td>
<td>1</td>
<td>N</td>
<td>3</td>
</tr>
</tbody>
</table>

F: Female, M: Male, Y: Yes, N: No, L: litres, %pred: percent predicted according to ERS reference values [90].
Restrictions in physical activity

In the beginning there were no obvious symptoms or restrictions in physical activity. As the disease progressed physical ability decreased. A successive deterioration and more symptoms of panting and heavy breathing became obvious. A sudden change – getting breathless during physical activity – was expressed as a contrast. The change in physical ability was expressed as loss of energy, a feeling of fatigue or becoming physically restricted compared to others.

Adaptation

Adaptation was a method to cope with symptoms, especially connected to physical activity. Avoiding or giving up physical activity were two ways of adaptation. Adjusting an activity could include slowing down the speed and intensity or stopping during the activity and using some breathing technique. There was also an intention to hide breathlessness. Other ways of adaptation were to neglect symptoms, not recognize restrictions or get used to coughing in the mornings.

Reflection

Reflection on the disease occurred at different time points and could start parallel to adaptation. When starting smoking the patients were not aware of
the risks of smoking. Statements about having exposed oneself voluntarily, and thereby damaging the lungs, revealed a sense of shame. This could cause delay in reflection on seeking advice. Poor physical condition, or ageing, were explanations for not being physically active.

Reflection on stopping smoking

Reflection on stopping smoking was a component of the reflection part of the process. It was influenced by media. Earlier experience of failing to give up smoking could stop the interviewee from considering it at this stage, i.e. resignation. A factor encouraging the patients to smoke was their unawareness of disease.

Reflection on seeking advice

Reflection on seeking advice could also be delayed. Patients refrained from talking about breathing problems, or did not seek medical advice due to insufficient knowledge of COPD. They also perceived the symptoms as too mild. Examples were given of seeking medical advice for symptoms and not being warned of the possibilities of developing a serious disease; nor getting a diagnosis of COPD.

Action

Take action illustrates the moment when the patients were ready to do something about their situation (Figure 2).

The subcategories Stopping smoking and Seeking advice from family, friends or health care were active steps. Support for Stopping smoking came from different sources. Encouragement from family and friends was important. Accelerating symptoms such as coughing strengthened the decision to stop smoking. Positive feed-back after having stopped, e.g. disappearance of the cough and secretions, and easier breathing, helped the patients to remain smoke-free.

Action was triggered by several factors. Contact with health care could lead to action such as support over Stopping smoking, Examinations or Getting a diagnosis. When acute symptoms appeared, the contact with health care could be at an emergency department or in primary care.

Some physicians never asked about smoking, while others always asked. The patients expected the physician to give an ultimate message to stop smoking.

Examinations

The most important examination from the patients’ viewpoint was the chest X ray. Spirometry was not known by the patients as an important test. Information about results from spirometry consisted of quantification of remaining or lost lung capacity. Knowing the results of examinations could affect attitudes to performing physical activity. The patients expected more
explanation of their results. Limited information about earlier results could influence them to continue smoking.

*Getting a diagnosis*

The diagnostic process was experienced as prolonged. There were uncertainties about a clear diagnosis, especially between asthma and COPD. When patients were informed about a COPD diagnosis, they were more willing to stop smoking.

In connection with getting the diagnosis, reflections about the future appeared. These included thoughts about worsening of symptoms, a need for oxygen support, mortality, uncertainty about ability to stop smoking, remorse and resignation: thinking about the ability to manage the problems and go on living with the disease, but also thinking of disease progress.

**Paper II**

**Characteristics**

Subjects with the three chronic diseases COPD, RA or DM were older than healthy subjects and their educational level and employment status were significantly lower (Table 4). There were more men in the COPD and DM groups and more women in the RA group. Current smokers and ex-smokers were most common among subjects with COPD. Economic problems were common for subjects with COPD and RA compared with subjects with DM and healthy individuals. More subjects with COPD lived alone.

**Physical activity**

Over 84% of the subjects with COPD had a low physical activity level. Compared with subjects with RA, DM and healthy subjects, this was significantly lower, also when adjusting for background data (Table 5 and Figure 3).
Table 4. Characteristics of the study population aged 40-84 years (n=10,755).

<table>
<thead>
<tr>
<th>Diseases</th>
<th>COPD n=526</th>
<th>RA n=1,120</th>
<th>DM n=2,149</th>
<th>Healthy n=6,960</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, yrs</strong></td>
<td>69.1</td>
<td>65.4</td>
<td>67.5</td>
<td>58.0</td>
</tr>
<tr>
<td></td>
<td>(68.3-69.9)</td>
<td>(64.7-66.1)</td>
<td>(67.1-68.0)</td>
<td>(57.7-58.3)</td>
</tr>
<tr>
<td><strong>Sex, females (%)</strong></td>
<td>44.3</td>
<td>64.8</td>
<td>42.8</td>
<td>52.7</td>
</tr>
<tr>
<td></td>
<td>(40.0-48.9)</td>
<td>(62.0-67.6)</td>
<td>(40.7-44.9)</td>
<td>(51.5-53.9)</td>
</tr>
<tr>
<td><strong>BMI (kg/m²)</strong></td>
<td>25.4</td>
<td>26.2</td>
<td>28.3</td>
<td>25.3</td>
</tr>
<tr>
<td><strong>Smoking status (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never smokers</td>
<td>12.1</td>
<td>45.3</td>
<td>46.8</td>
<td>52.5</td>
</tr>
<tr>
<td></td>
<td>(9.3-15.0)</td>
<td>(42.4-48.3)</td>
<td>(44.7-49.0)</td>
<td>(51.4-53.7)</td>
</tr>
<tr>
<td>Ex-smokers</td>
<td>53.0</td>
<td>31.1</td>
<td>39.3</td>
<td>27.3</td>
</tr>
<tr>
<td></td>
<td>(48.7-57.4)</td>
<td>(28.3-33.8)</td>
<td>(37.3-41.4)</td>
<td>(26.2-28.3)</td>
</tr>
<tr>
<td>Current smokers</td>
<td>34.8</td>
<td>23.6</td>
<td>13.8</td>
<td>20.2</td>
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<tr>
<td><strong>Highest educational level (%)</strong></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Compulsory school</td>
<td>68.7</td>
<td>56.3</td>
<td>63.0</td>
<td>38.7</td>
</tr>
<tr>
<td></td>
<td>(64.7-72.8)</td>
<td>(53.3-59.3)</td>
<td>(60.9-65.1)</td>
<td>(37.5-39.8)</td>
</tr>
<tr>
<td>Grammar school</td>
<td>12.0</td>
<td>20.8</td>
<td>16.0</td>
<td>29.8</td>
</tr>
<tr>
<td></td>
<td>(9.2-14.9)</td>
<td>(18.3-23.2)</td>
<td>(14.4-17.6)</td>
<td>(28.7-30.9)</td>
</tr>
<tr>
<td>University</td>
<td>12.2</td>
<td>14.6</td>
<td>12.5</td>
<td>25.9</td>
</tr>
<tr>
<td></td>
<td>(9.3-15.1)</td>
<td>(12.5-16.7)</td>
<td>(11.1-13.9)</td>
<td>(24.8-27.0)</td>
</tr>
<tr>
<td>Other</td>
<td>7.0</td>
<td>8.3</td>
<td>8.4</td>
<td>5.6</td>
</tr>
<tr>
<td></td>
<td>(4.8-9.3)</td>
<td>(6.7-10.0)</td>
<td>(7.2-9.6)</td>
<td>(5.1-6.2)</td>
</tr>
<tr>
<td><strong>Employment (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed or studying</td>
<td>19.0</td>
<td>27.1</td>
<td>26.2</td>
<td>66.6</td>
</tr>
<tr>
<td></td>
<td>(15.6-22.4)</td>
<td>(24.4-29.7)</td>
<td>(24.3-28.1)</td>
<td>(65.5-67.8)</td>
</tr>
<tr>
<td>Sick leave or sickness pension</td>
<td>13.5</td>
<td>18.7</td>
<td>10.7</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>(10.6-16.4)</td>
<td>(16.5-21.0)</td>
<td>(9.4-12.0)</td>
<td>(1.4-2.0)</td>
</tr>
<tr>
<td>Retired</td>
<td>66.7</td>
<td>52.9</td>
<td>59.7</td>
<td>28.0</td>
</tr>
<tr>
<td></td>
<td>(62.7-70.8)</td>
<td>(50.0-55.9)</td>
<td>(57.7-61.8)</td>
<td>(27.0-29.1)</td>
</tr>
<tr>
<td><strong>Economic problems (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>15.6</td>
<td>15.4</td>
<td>9.5</td>
<td>7.9</td>
</tr>
<tr>
<td></td>
<td>(12.4-18.7)</td>
<td>(13.3-17.6)</td>
<td>(8.3-10.8)</td>
<td>(7.2-8.5)</td>
</tr>
<tr>
<td><strong>Living alone (%)</strong></td>
<td>36.3</td>
<td>29.3</td>
<td>26.7</td>
<td>17.3</td>
</tr>
<tr>
<td></td>
<td>(32.2-40.4)</td>
<td>(26.6-32.0)</td>
<td>(24.8-28.5)</td>
<td>(16.4-18.2)</td>
</tr>
</tbody>
</table>

Data are presented as percentage or mean with 95% confidence intervals within brackets.
COPD: Chronic obstructive pulmonary disease (not RA, not DM), RA: Rheumatoid arthritis (not COPD, not DM), DM: Diabetes mellitus (not COPD, not RA), Healthy: subjects with no diseases or impairments, BMI: Body Mass Index.
Table 5. Physical activity level (n=10,755).

<table>
<thead>
<tr>
<th>Diseases</th>
<th>COPD n=526</th>
<th>RA n=1,120</th>
<th>DM n=2,149</th>
<th>Healthy n=6,960</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>High activity level</strong> °/</td>
<td>15.8</td>
<td>25.6</td>
<td>27.5</td>
<td>39.8</td>
</tr>
<tr>
<td><strong>Low activity level</strong> °/</td>
<td>84.2</td>
<td>74.4</td>
<td>72.5</td>
<td>60.2</td>
</tr>
<tr>
<td>OR* (95% CI)</td>
<td>1</td>
<td>1.80 (1.33-2.45)</td>
<td>2.17 (1.63-2.90)</td>
<td>2.49 (1.88-3.28)</td>
</tr>
</tbody>
</table>

Data are presented as percentage with odds ratio and 95% confidence intervals within brackets. COPD: Chronic obstructive pulmonary disease, RA: Rheumatoid arthritis, DM: Diabetes mellitus, OR: odds ratio, CI: confidence interval.

°/ moderate regular exercise (high activity >30 minutes, 1-2 times a week) or regular exercise and training (high activity >30 minutes ≥3 times a week),

°/ sedentary lifestyle (mostly sitting down or low activity <2 hours a week) or moderate exercise (low activity >2 hours a week).

* The adjusted odds ratio expresses the likeliness of higher activity level in the non-COPD groups compared to the COPD group after adjusting for sex, age, smoking, BMI, educational level, employment status, economic problems and living alone.

Figure 3. Physical activity. Answer to the question: “How much have you moved about and exerted yourself physically in your free time during the past 12 months?” Adjusting for background data and dichotomizing results: A and B: low activity level (not enough to maintain health) and C and D: high activity level (enough to maintain health) resulted in significant differences (p<0.001) between COPD and the other groups in a logistic regression analysis.
Health-related quality of life

General health was rated as poor or very poor by 31% of subjects with COPD and by 29% of subjects with RA, which was significantly higher than in subjects with DM (16%) (p<0.001).

Health-related quality of life, as assessed with EQ-5D index, was worse (lower index) in subjects with the three chronic diseases compared to healthy subjects (Table 6 and Figure 4). Subjects with COPD had significantly lower index than subjects with DM.

Subjects with COPD or RA generally had the highest prevalence of problems in each dimension. Odds ratios adjusted for background data indicated that subjects with COPD had significantly more problems of anxiety/depression than the other groups, while subjects with RA had significantly more mobility problems and pain/discomfort, than those with COPD and DM.

Table 6. The EQ-5D index and percentages of subjects reporting any problems (moderate or severe problems) in different dimensions of the EQ-5D (n=10,755).

<table>
<thead>
<tr>
<th>Diseases</th>
<th>COPD (n=526)</th>
<th>RA (n=1,120)</th>
<th>DM (n=2,149)</th>
<th>Healthy (n=6,960)</th>
</tr>
</thead>
<tbody>
<tr>
<td>EQ-5D index value, mean (SD)</td>
<td>0.62 (0.27)</td>
<td>0.60 (0.27)</td>
<td>0.72 (0.25)</td>
<td>0.91 (0.12)</td>
</tr>
<tr>
<td>Mobility</td>
<td>48.4</td>
<td>55.3</td>
<td>36.1</td>
<td>3.6</td>
</tr>
<tr>
<td>OR* (95% CI)</td>
<td>1</td>
<td>1.75 (1.37-2.22)</td>
<td>0.63 (0.50-0.79)</td>
<td>0.10 (0.07-0.12)</td>
</tr>
<tr>
<td>Self-Care</td>
<td>9.1</td>
<td>12.1</td>
<td>7.2</td>
<td>0.3</td>
</tr>
<tr>
<td>OR* (95% CI)</td>
<td>1</td>
<td>1.49 (0.98-2.22)</td>
<td>0.84 (0.56-1.27)</td>
<td>0.07 (0.04-0.13)</td>
</tr>
<tr>
<td>Usual Activities</td>
<td>38.5</td>
<td>38.0</td>
<td>23.40</td>
<td>0.9</td>
</tr>
<tr>
<td>OR* (95% CI)</td>
<td>1</td>
<td>0.93 (0.72-1.20)</td>
<td>0.48 (0.38-0.62)</td>
<td>0.03 (0.02-0.04)</td>
</tr>
<tr>
<td>Pain/Discomfort</td>
<td>87.3</td>
<td>96.1</td>
<td>74.8</td>
<td>34.8</td>
</tr>
<tr>
<td>OR* (95% CI)</td>
<td>1</td>
<td>3.85 (2.50-5.88)</td>
<td>0.43 (0.32-0.58)</td>
<td>0.11 (0.08-0.14)</td>
</tr>
<tr>
<td>Anxiety/ Depression</td>
<td>52.6</td>
<td>47.4</td>
<td>34.9</td>
<td>15.5</td>
</tr>
<tr>
<td>OR* (95% CI)</td>
<td>1</td>
<td>0.64 (0.50-0.81)</td>
<td>0.47 (0.38-0.59)</td>
<td>0.18 (0.14-0.22)</td>
</tr>
</tbody>
</table>

Data are presented as mean and standard deviation (SD) or percentage with odds ratio and 95% confidence intervals within brackets.

EQ-5D: The EuroQol five-dimension questionnaire, COPD: Chronic obstructive pulmonary disease, RA: Rheumatoid arthritis, DM: Diabetes mellitus, OR: odds ratio, CI: confidence interval.

* The adjusted odds ratio expresses the likeliness of reporting a problem in the non-COPD groups compared to the COPD group after adjusting for sex, age, smoking, BMI, educational level, employment status, economic problems and living alone.
**Figure 4.** The five dimensions of EQ-5D and the comparison groups of the study. Percentages of subjects with any problem.
COPD: Chronic obstructive pulmonary disease, RA: Rheumatoid arthritis, DM: Diabetes mellitus, EQ-5D: The EuroQol five-dimension questionnaire.

**Psychological health and symptoms**
Impaired psychological well-being, measured by GHQ12, was more common among subjects with COPD or RA than among subjects with DM or healthy subjects. Subjects with COPD had a significantly higher level of impairment than any of the other groups, after adjusting for background data. Subjects with COPD also had a significantly higher prevalence of anxiety and depression. In addition, they were more likely to have a pessimistic view of the future than any of the other groups. Subjects with COPD or RA had a significantly higher prevalence of sleeping problems and fatigue than subjects with DM or healthy subjects.

**Gender differences**
Women had a significantly higher prevalence of anxiety, depression and sleep disturbances than men in all disease groups as well as in the group of healthy subjects.
Paper III

The mean age was 69.1 years (females 67.0 and males 69.9 years), and more men than women had self-reported COPD (Table 7). One-third were current smokers with daily smoking in 28% of all subjects. A total of 83% reported physical activity on the two lowest levels, with no difference between the years 2004 and 2008, and a sedentary life-style was stated by 39%. Compulsory school was the highest educational level in 57% and over 84% were retired, on sick leave or had sickness pension. Comorbidity was present with cardiovascular disease in 34%, hypertension, or asthma in over 40%, depression in 26% and chronic fatigue syndrome in 22%.

More than 23% had visited an emergency department during the past three months, compared with 8-9% in age-matched subjects without COPD, and 14% had been admitted to hospital.

General health status was reported as very good/good in 24% and psychological well-being was not impaired in 77%. Quality of life (EQ-5D) was graded as “no problems” by half the subjects regarding mobility and anxiety/depression, while 14% had no problems with pain/discomfort and over 60% had no problems with usual activities.

A slightly better status of the health and quality of life measures was seen in 2008 compared with 2004.

Factors associated with better self-rated health and quality of life were: higher level of physical activity, social support, absence of economic problems, high educational level, and never smoked/stopped smoking (Table 8). Subjects with the highest level of physical activity had the best health and quality of life, but the odds ratio was good (OR 2.40 (95%CI 1.88-3.06)) even for subjects with low activity, compared with sedentary level. Relations between reported health status and level of physical activity are described in Figure 5.

Age was significantly associated with all outcome measures, while sex was not. When adjusting for comorbidity, “never having smoked” was associated with better status on all health measures.

Among comorbid conditions, cardiovascular disease, depression, and chronic fatigue syndrome were negatively associated with health and quality of life, while hypertension and asthma showed no significant associations. Alcohol use had no significant associations in the reduced model (Table 8), with or without comorbidity.
Table 7. Characteristics of the subjects in paper III (n=1,475).

<table>
<thead>
<tr>
<th></th>
<th>Combined 2004+2008 n=1,475</th>
<th>2004 n=664</th>
<th>2008 n=811</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, yrs.</strong></td>
<td>69.1 (9.7)</td>
<td>68.9 (9.8)</td>
<td>69.3 (9.6)</td>
<td>0.25</td>
</tr>
<tr>
<td><strong>Sex, females (%)</strong></td>
<td>46.0</td>
<td>43.8</td>
<td>47.8</td>
<td>0.06</td>
</tr>
<tr>
<td><strong>BMI (kg/m²)</strong></td>
<td>26.1 (5.0)</td>
<td>25.9 (4.7)</td>
<td>26.3 (5.3)</td>
<td>0.10</td>
</tr>
<tr>
<td><strong>Economic problems (%)</strong></td>
<td>15.0</td>
<td>16.1</td>
<td>14.1</td>
<td>0.14</td>
</tr>
<tr>
<td><strong>Alcohol use the past 12 months (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-4 times a month or more</td>
<td>48.7</td>
<td>48.1</td>
<td>49.2</td>
<td>0.34</td>
</tr>
<tr>
<td>Once a month or less / never</td>
<td>51.3</td>
<td>51.9</td>
<td>50.8</td>
<td>0.34</td>
</tr>
<tr>
<td><strong>Highest educational level (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compulsory school</td>
<td>57.3</td>
<td>67.8</td>
<td>54.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Grammar school</td>
<td>16.1</td>
<td>13.2</td>
<td>18.5</td>
<td>0.003</td>
</tr>
<tr>
<td>University</td>
<td>12.3</td>
<td>11.1</td>
<td>13.3</td>
<td>0.10</td>
</tr>
<tr>
<td>Other</td>
<td>10.9</td>
<td>7.8</td>
<td>13.4</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Social support (%)</strong></td>
<td>90.9</td>
<td>90.9</td>
<td>90.9</td>
<td>0.50</td>
</tr>
<tr>
<td><strong>Smoking status (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never smokers</td>
<td>12.3</td>
<td>13.6</td>
<td>11.2</td>
<td>0.08</td>
</tr>
<tr>
<td>Ex-smokers</td>
<td>54.6</td>
<td>52.2</td>
<td>56.6</td>
<td>0.05</td>
</tr>
<tr>
<td>Current smokers</td>
<td>33.1</td>
<td>34.2</td>
<td>32.2</td>
<td>0.21</td>
</tr>
<tr>
<td><strong>Physical activity (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sedentary</td>
<td>39.3</td>
<td>40.5</td>
<td>38.3</td>
<td>0.19</td>
</tr>
<tr>
<td>Moderate exercise (low activity)</td>
<td>43.7</td>
<td>43.4</td>
<td>44.0</td>
<td>0.41</td>
</tr>
<tr>
<td>Moderate regular exercise</td>
<td>11.4</td>
<td>10.8</td>
<td>11.9</td>
<td>0.25</td>
</tr>
<tr>
<td>Regular exercise and training</td>
<td>5.6</td>
<td>5.3</td>
<td>5.8</td>
<td>0.34</td>
</tr>
<tr>
<td><strong>Employment status (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed or studying</td>
<td>15.9</td>
<td>14.4</td>
<td>17.2</td>
<td>0.07</td>
</tr>
<tr>
<td>Sick leave or sickness pension</td>
<td>13.8</td>
<td>13.9</td>
<td>13.8</td>
<td>0.48</td>
</tr>
<tr>
<td>Retired</td>
<td>70.3</td>
<td>71.7</td>
<td>69.1</td>
<td>0.14</td>
</tr>
<tr>
<td><strong>Comorbidity factors (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>33.8</td>
<td>35.5</td>
<td>32.5</td>
<td>0.11</td>
</tr>
<tr>
<td>Hypertension</td>
<td>45.3</td>
<td>44.9</td>
<td>45.5</td>
<td>0.41</td>
</tr>
<tr>
<td>Asthma</td>
<td>42.8</td>
<td>45.9</td>
<td>40.3</td>
<td>0.02</td>
</tr>
<tr>
<td>Depression</td>
<td>26.2</td>
<td>27.3</td>
<td>25.3</td>
<td>0.19</td>
</tr>
<tr>
<td>Chronic fatigue syndrome</td>
<td>21.8</td>
<td>23.3</td>
<td>20.6</td>
<td>0.11</td>
</tr>
</tbody>
</table>

Data are presented as mean and standard deviation (SD) or percentage. Differences are tested between the years 2004 and 2008 with Student’s t-test for age and BMI. Differences between proportions are tested using the asymptotic normal test for binomial data.

BMI: Body Mass Index, Economic problems: Difficulty in managing current expenditure during the past 12 months.
Table 8. Associations between background factors and measures of general health and quality of life.

<table>
<thead>
<tr>
<th></th>
<th>General health OR (95%CI)</th>
<th>GHQ12 OR (95%CI)</th>
<th>EQ-5D OR (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Economic problems</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, 6-12 months</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
</tr>
<tr>
<td>Yes, 3-5 months</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Yes, 2 months</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Yes, 1 month</td>
<td>ns</td>
<td>ns</td>
<td>2.69 (1.27-5.73)</td>
</tr>
<tr>
<td>No</td>
<td>1.89 (1.08-3.33)</td>
<td>2.33 (1.35-4.03)</td>
<td>3.03 (1.80-5.11)</td>
</tr>
<tr>
<td><strong>Alcohol use the past 12 months</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 times a week or more</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
</tr>
<tr>
<td>2-3 times a week</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>2-4 times a month</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Once a month or less</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Never</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td><strong>Highest educational level</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compulsory school</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
</tr>
<tr>
<td>Grammar school</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>University</td>
<td>ns</td>
<td>ns</td>
<td>1.59 (1.15-2.21)</td>
</tr>
<tr>
<td>Other</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td><strong>Social support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
</tr>
<tr>
<td>Presumably not</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Yes, probably</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Yes, undoubtedly</td>
<td>1.88 (1.08-3.27)</td>
<td>2.69 (1.57-4.61)</td>
<td>1.61 (0.62-2.73)</td>
</tr>
<tr>
<td><strong>Smoking status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, I smoke daily</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
</tr>
<tr>
<td>Yes, I smoke sometimes</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>No, I have stopped smoking</td>
<td>ns</td>
<td>1.37 (1.04-1.80)</td>
<td>ns</td>
</tr>
<tr>
<td>No, I have never smoked</td>
<td>1.57 (1.07-2.30)</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td><strong>Physical activity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sedentary</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
<td>1 (ref)</td>
</tr>
<tr>
<td>Moderate exercise (low activity)</td>
<td>2.40 (1.88-3.06)</td>
<td>1.90 (1.47-2.44)</td>
<td>1.92 (1.53-2.42)</td>
</tr>
<tr>
<td>Moderate regular exercise</td>
<td>3.59 (2.47-5.22)</td>
<td>2.02 (1.34-3.04)</td>
<td>2.41 (1.68-3.45)</td>
</tr>
<tr>
<td>Regular exercise and training</td>
<td>7.57 (4.57-12.55)</td>
<td>2.51 (1.38-4.56)</td>
<td>3.17 (1.97-5.10)</td>
</tr>
</tbody>
</table>

Data are presented as odds ratios (OR) and 95% confidence intervals within brackets. GHQ12, General Health Questionnaire 12 item version; EQ-5D, EuroQol five-dimension questionnaire index; ref=reference value; ns=not significant association; BMI, Body Mass Index; Economic problems: Difficulty in managing current expenditure during the past 12 months; Social support was assessed according to the question: "Do you have any persons in your vicinity who can give you personal support in case of personal problems or life crises?".
Figure 5. Relations between self-rated general health (X-axis) and physical activity in leisure time.
Paper IV

Diagnostic spirometry

Of the 533 patients with new diagnosis of COPD, diagnostic spirometry data were available in 59% (316 patients) (Figure 6). Patients with spirometry data were younger (Table 9). Men >50 years were more likely to have spirometry data than were women >50 years (p=0.004). Spirometry data were more absent in primary care records: 47% versus 20% in secondary care (p<0.001).

Post-bronchodilator spirometry data including $\text{FEV}_1/\text{VC}$ ratio were available in 241 patients (45% of all those with new diagnoses). Patients with post-bronchodilator data had more smoking years than those without such data.

In the 241 patients with post-bronchodilator data, 81 (34%) had a post-bronchodilator $\text{FEV}_1/\text{VC}$ ratio above the diagnostic criterion of 0.70 [3]. This group was younger, contained more women, had a higher body mass index and was more often current smokers. In addition, more than half had a predicted $\text{FEV}_1$ of over 80%, equivalent to $\text{FEV}_1$ limits for COPD in the NICE guidelines [94].

![Figure 6](image-url)  
*Figure 6*. Distribution of post-bronchodilator spirometry data and absence of data in medical records in patients with new diagnosis of COPD (n=533).
Table 9. Characteristics of the study population stratified by whether spirometry data were available in connection with new diagnosis of COPD, (n=533).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>New Diagnosis (n=533)</th>
<th>Spirometry Data (n=316)</th>
<th>No Spirometry Data (n=217)</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, yrs</td>
<td>60.1 (8.0)</td>
<td>59.2 (8.3)</td>
<td>61.4 (7.4)</td>
<td>0.002</td>
</tr>
<tr>
<td>Gender, female, %</td>
<td>58</td>
<td>56</td>
<td>61</td>
<td>0.232</td>
</tr>
<tr>
<td>Body mass index (kg/m²)</td>
<td>26.3 (5.0)</td>
<td>26.1 (4.8)</td>
<td>26.7 (5.3)</td>
<td>0.176</td>
</tr>
<tr>
<td>Smoking status*, %</td>
<td>0.836</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current smokers</td>
<td>40</td>
<td>41</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>Years smoking*, yrs</td>
<td>36.1 (11.5)</td>
<td>35.9 (11.2)</td>
<td>36.4 (12.0)</td>
<td>0.671</td>
</tr>
<tr>
<td>Highest educational level, %</td>
<td>0.324</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compulsory school</td>
<td>63</td>
<td>61</td>
<td>66</td>
<td></td>
</tr>
<tr>
<td>Grammar school / University</td>
<td>37</td>
<td>39</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td>Spirometry data within each age group, %</td>
<td>0.001</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;50 yrs</td>
<td>76</td>
<td>24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-65 yrs</td>
<td>64</td>
<td>36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;65 yrs</td>
<td>51</td>
<td>49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Setting; primary care, %</td>
<td>76</td>
<td>68</td>
<td>89</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Data are presented as mean and standard deviation (SD) or percentage.

*Smoking according to patient questionnaire in 2005.

Quality of spirometry

Flow-volume curves were available for 207 patients and 55% of these fulfilled the present quality criteria (Table 10). Volume-time curves were available for 119 patients and 34% of these fulfilled the criteria.

Acceptable quality was found for the start, peak and no-artefacts criteria in more than 90% of the tests (Table 10), while end-of-test was reached in 64-65% and FET ≥6 seconds in 51%. Further, FET ≥6 seconds was present in 14% of the patients under 50 years and 67% of patients over 65 years (p=0.002).

In 24%, 75 out of 316, of the spirometry tests performed in connection with diagnosis, there were no post-bronchodilator values or FEV₁/VC ratio. Post-bronchodilator values of SVC were recorded in one-quarter and FVC in three-quarters of patients who underwent spirometry. In the reports giving both values (n=65), 40% had a post-bronchodilator FVC higher than SVC.
Table 10. Quality criteria in post-bronchodilator FEV1/VC ratio <0.70 and FEV1/VC ratio ≥0.70, (n=207).

<table>
<thead>
<tr>
<th>Quality criteria</th>
<th>All</th>
<th>FEV₁/ VC ratio &lt;0.70</th>
<th>FEV₁/ VC ratio ≥0.70</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Flow-volume curve</strong></td>
<td>n=207</td>
<td>n=133</td>
<td>n=74</td>
<td></td>
</tr>
<tr>
<td>Start of test, steep upslope</td>
<td>94</td>
<td>94</td>
<td>93</td>
<td>0.984</td>
</tr>
<tr>
<td>Peak, sharp</td>
<td>94</td>
<td>97</td>
<td>88</td>
<td>0.087</td>
</tr>
<tr>
<td>No artefacts</td>
<td>93</td>
<td>92</td>
<td>93</td>
<td>0.938</td>
</tr>
<tr>
<td>End-of-test, no cutoff</td>
<td>64</td>
<td>61</td>
<td>69</td>
<td>0.178</td>
</tr>
<tr>
<td>All (4) criteria fulfilled</td>
<td>55</td>
<td>54</td>
<td>57</td>
<td>0.828</td>
</tr>
<tr>
<td><strong>Volume-time curve</strong></td>
<td>n=119</td>
<td>n=75</td>
<td>n=44</td>
<td>0.765</td>
</tr>
<tr>
<td>End-of-test, acceptable plateau a</td>
<td>65</td>
<td>57</td>
<td>77</td>
<td>0.252</td>
</tr>
<tr>
<td>FET ≥6 s a</td>
<td>51</td>
<td>68</td>
<td>23</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>All (2) criteria fulfilled a</td>
<td>34</td>
<td>44</td>
<td>18</td>
<td>0.008</td>
</tr>
</tbody>
</table>

Data are presented as percentage.
FET = forced expiratory time.
a Percentage of volume-time curves.
Discussion

At the time of diagnosis

Paper I demonstrates a process model where “Consequences of smoking” was the core category. Restrictions in physical activity were an indicator of emerging disease and was also expressed as a loss of energy, a feeling of fatigue, or becoming physically restricted compared with others. During the analyses a main category “Shame” emerged, which interacted with other categories and was an obstacle for seeking help.

In the early stages of COPD it is important to gain an understanding of the patient’s thoughts and reflections on the signs of disease. An early sign of developing COPD can, according to the proposed model, be “Restrictions in physical activity”. This is supported by the hypothesis suggested by Polkey and Rabe [76], that reduced physical activity is an early feature of COPD leading to muscle atrophy instead of systemic inflammation as the main driver of generalised muscle atrophy. Perhaps the perception of breathlessness during activity adds to the decreased willingness to be physically active.

There are many steps before the patient “takes action” by for example quitting smoking as a behaviour change. There is a risk that a patient’s perception of the disease as self-inflicted might postpone the decision to seek help. Further, the feelings of shame of being a smoker or feelings of guilt for smoking could delay initiating the help process.

In paper I the emerging main category was labelled “shame”. However, “guilt” could be considered a suitable alternative label. Lazare [95] discusses shame and humiliation, and points out some differences in the experiences of guilt and shame. With shame the response is to hide or disappear while with guilt the response is to make amends. Shame is all-encompassing, often embracing one’s total identity, while guilt is usually restricted to one aspect of the self that may be considered separate from other aspects of the self. Shame and guilt often occur together. To diminish shame in the medical encounter Lazare presents twelve clinical strategies for the management of shame and recommends heightened awareness of these issues to diminish the shame experience.

Malterud and Hollmågel present “The Awareness Model” as a strategy to avoid humiliations in the clinical encounter [96]. Smith et al [97] make a synthesis of patients’ help-seeking and delay in cancer presentation, where
fear of consultation with respect to embarrassment and to the idea of cancer itself is a main theme. The sanctioning of help-seeking is central and might arise from the media or friends and family. With reference to Smith’s study Malterud discusses patient fear of embarrassment and poses the question as to what the medical consequences of shame and blame are. Chapple et al [97] highlight the feeling of stigmatisation and shame among lung cancer patients because of the disease’s strong association with smoking. This can be compared to the COPD patient’s feeling of shame, although patients feel they are unjustly blamed for their illness having stopped smoking years earlier. Chapple means that interventions should be presented with care so as not to add to the stigma experienced by patients with lung cancer and other smoking related diseases.

An open attitude and individually tailored approach, based on the patient as an individual, is supported in a qualitative study by Butler et al [98] and is in agreement with the motivational interviewing concept, recently reviewed in the Cochrane database (2010) [99].

The term “smoker’s lung” has been used to underpin smoking as a risk factor for developing COPD and to support smoking cessation [100]. The information of smoking as the most important risk factor in COPD has succeeded and thus “smoker’s lung” has perhaps become an obstacle for persons seeking advice for developing COPD. This can be supported by paper I, where shame was a category emerging during the analysis and interfering with other categories. A person with suspected COPD is probably aware of smoking as a contributor to the disease. The attitudes of health professionals presenting the patient as “an individual who sometimes smokes” instead of labelling the person directly as a “smoker”, could perhaps be a support in the process of quitting smoking.

Method discussion
Because of the intention of recruiting patients newly diagnosed or with suspected COPD, four patients had no spirometry results at the time of the interview. Standardised spirometry was performed on all patients after the interview to avoid for example, discussing spirometry results during the interview.

The selection of patients limited the applicability of this study to current or former smokers while COPD was being diagnosed.

Grounded theory requires continuous theoretical sampling to direct further data collection. Given the limited number of possible patients, sampling was mainly purposeful and intended to describe the research area. This is in line with the grounded theory concept, which “… starts in a site, without knowing what the research question or main concern is until it emerges” [80]. The present sampling strategies represent an adaptation to real-world conditions: the strategies met the information needs of the study [101]. Finally, although we attempted to generate categories and a model strictly
from empirical data, it cannot be excluded that the author’s preconceptions may have influenced the results and conclusions of the study. Further studies are needed to shed light on this, as well as on the relative importance of the different categories identified in this study based on a limited number of informants.

Public health survey “Liv och hälsa” (Life and health)

Paper II compares subjects with COPD with RA, DM, and healthy subjects in the population. Physical activity was overall low, where COPD subjects had the lowest activity and rated general health most poorly compared to the other groups. Pain/discomfort was rated high among all groups and highest among RA subjects.

Paper III has shown that subjects with COPD combined with good health and quality of life are physically active. The higher the physical activity levels the better their health and quality of life. Even a low level of physical activity is better compared to a sedentary lifestyle.

The results are in accordance with Garcia-Aymerich et al (2009) [102] who, in an epidemiological study, assessed daily life activities in subjects with COPD and found associations between higher levels of regular physical activity and better functional status. They also showed that physically active subjects with COPD had a lower risk of COPD admissions and mortality [103]. They proposed that physical activity should be widely recommended for patients with COPD in COPD guidelines [102]. Pitta et al [37], has shown that encouragement to be more active in daily life is an important part of the management of patients with COPD.

Selection of subjects

One strength of the present method is that it is population based, i.e., health status in subjects in the general population was investigated. This is in contrast to other studies where study groups were recruited mainly from the health care system. The present studies reflect the subjects’ own perceptions of having or not having a diagnosis, which could be a strength but also raises questions about the precision of disease terms. However, the questionnaire did not focus on respiratory problems. Moreover, on the diagnosis list, the COPD diagnosis was, perhaps, not the primary diagnosis of choice. This could indicate that subjects with more severe disease, where a COPD diagnosis was clearly expressed, were included in the present study.

The estimated prevalence of COPD for Swedes over 45 years of age is 5-15% [13], in adults with RA, 0.5-2.7% [104], and in adults (25-64 years) with DM, 3% [105]. In addition the prevalence of DM increases sharply with increased age [106]. Thus, in the present studies an over-reporting of RA and under-reporting of COPD is present. Self-reported RA probably includes
other polyarthritic, systemic autoimmune diseases and subjects with arthropathies as well as osteoarthritis, whereas in population-based studies of COPD, objective definitions tend to produce higher prevalence estimates than do patient-reported diagnoses [12]. Self-reported DM in other studies has been found to have a high specificity [107]. The high prevalence of DM was therefore probably explained by the relatively high mean age of our population. The surprisingly higher prevalence of RA and DM indicates that these two groups included individuals with fewer symptoms and thereby a better health status.

On the other hand, the prevalence of COPD was lower than expected which implies a selection of subjects with greater comorbidity and a lower health status in this diagnostic group. This is supported by the opinion of Nihlén et al [108], that self-reporting of a physician’s diagnosis of COPD is assessed to represent a clinically significant disease of sufficient severity to visit a physician. The prevalence of self-reported COPD in the present studies was low compared to other studies; both from southern Sweden for chronic bronchitis and/or emphysema (CBE) [109] and COPD in addition to CBE [108], and in northern Sweden [13].

**Physical activity**

A weakness regarding physical activity is its evaluation by a single question describing activity in leisure time. However, physical strain in relation to work is not applicable in these studies whereas 70 to 84 percent of the subjects with chronic diseases are either retired, on sick leave or have sickness pension. The physical activity question has its origin in a study by Saltin et al [88], and is frequently used in public surveys. It has been shown to be valid for categorising people into different categories of activity [89].

It is important to stress that the use of questionnaires cannot accurately assess physical activity in daily life [110]. There is ongoing research on activity monitoring with possibilities to assess variables as steps and time spent in physical activities depending on the device used [77, 111-116].

It is stated that inactivity starts early in the disease [110], and thus, exercise therapy should begin as early as possible in the disease process [117].

Multidisciplinary pulmonary rehabilitation is a basis for treatment of COPD, with evidence for improvement in exercise endurance, dyspnoea, functional capacity and quality of life [37]. In the rehabilitation concept, exercise training is a cornerstone [51]. As the majority of patients with COPD are treated in primary care, it is important to enable them to enter programmes including physical training in primary care settings [118]. However, better functional status was associated with daily life activities rather than planned exercise activities [102], which is encouraging because regular spontaneous physical activity is easier for the majority of subjects with COPD. In a recent study, Watz et al [77] investigated physical activity in patients with COPD and found that physical activity was already reduced
from GOLD Stage II [3], which suggests that patients spontaneously chose to reduce their activity rather than be restricted by pulmonary limitation, which implies a possible influenceable behavioural component.

**Method discussion**

The design of the present studies was cross-sectional and therefore no causal associations could be verified. In comparison to studies directly aimed at subjects with respiratory symptoms this population survey did not contain questions on specific respiratory symptoms, nor were there any instruments enabling grading severity of disease. The response rate in the present studies was approximately 65-70%, with a possible underestimation of smoking habits according to a study of non-responders in a large scale questionnaire survey on respiratory health in Sweden [119]. Non-responders did not differ significantly in prevalence of airway diseases or symptoms when compared with responders. Male sex, young age and smokers were underestimated among non-responders. There was, however, no sign of bias in disease and symptom prevalence in that study.

The global perception of health status was, in Papers II and III, measured by a single question according to the same principle as in other studies [52, 68, 120]. In addition, Idler *et al* concluded in a review, that self-ratings provide the respondents’ views of global health status in a way that nothing else can [121].

**Spirometry in clinical practice**

Paper IV describes the documentation of spirometry data in medical records for patients with a new diagnosis of COPD. Only 30% had a diagnosis verified by spirometry data very low considering that spirometry is thought to confirm the diagnosis. Other studies did not have a design comparable to ours including evaluation of spirometry in combination with diagnosis.

In total, spirometry data in records were available for 59% of patients in the present study, and post-bronchodilator values were included in 76% of these. These results are higher than data from health plans in a United States (US) study [122], where 32% of patients with new COPD diagnoses had undergone spirometry with post-bronchodilator values in 46% of these patients. In primary care in Spain [123], spirometric results were obtained in 58% of patients diagnosed with COPD and with post-bronchodilator data in 55% of these patients. In Wales [124], 37% of spirometric confirmation was present, as estimated from one question to general practitioners, while in the US Veterans Administration [125], 34% of patients with a new diagnosis of COPD had undergone spirometry.
Method discussion
Patients with COPD were randomly selected from the diagnosis registers. This could result in a selection of patients with an established diagnosis and more severe COPD in comparison with patients with minor symptoms and without registered COPD diagnoses perhaps labelled with asthma diagnoses and not COPD.

Quality of spirometry
All quality criteria were met in 34% to 55% of the available spirometry curves in paper IV (Table 10).

It was not possible to assess in detail the start of the forced manoeuvre with possible overestimation of FEV$_1$ because of sub-maximal efforts and/or hesitation in the start-of-test phase as described in the BRONCUS study [126]. The between-manoeuvre criterion repeatability [127], could not be assessed in a standardized manner because of the different devices and software used. Moreover in most cases there was only one curve, “the best curve” – the one with the largest sum of FEV$_1$ and FVC in the report.

Despite the limited possibilities of analysing in detail the quality of performance parameters, there were indications that FET was the main parameter associated with detection of airflow limitation. The importance of this is emphasized by Schermer et al [128], who found that sufficient duration of FET was the quality marker with the highest rate of inadequacy. In our study, visual analysis of only the start, peak, artefacts or end-of-test from the curves showed no clear relationship affecting the FEV$_1$/VC ratio. However FET ≥6 seconds was achieved by only 51% in our study, indicating sub-maximal exhalations.

Fifteen percent of the patients with newly diagnosed COPD had an FEV$_1$/VC ratio equal to or greater than 0.70 indicating no airflow limitation. Diagnosis based mainly on clinical symptoms, not taking spirometric data into consideration or misinterpreting available data could be reasons for this overdiagnosis. A desire to alert smokers to the danger of serious disease could perhaps be an explanation for the high prevalence of women (with high smoking rates) and younger persons in this group.

Half the patients with FEV$_1$/VC ratios over 0.70 also had predicted FEV$_1$ of over 80%. This may indicate that only a minor airflow limitation was present and supports a suspicion of misinterpretation of the spirometry data.
General remarks

Smoking
There was a high prevalence of smoking among subjects with COPD, i.e. in papers II and III, where 28% smoked daily. Compared with smoking in the adult population in Sweden; 11% of men and 13% of women are daily smokers [129]. Thus, there are possibilities to reduce the prevalence of this important risk factor in subjects with COPD. Non-smoking is a health supporting factor, but there is a worrying trend of higher prevalence of smoking among women, especially in younger age groups [130].

Physical activity
The low level of physical activity (PA) in the disease groups might have been a result of having had a chronic disease for many years. It is known that many subjects with COPD adapt to the disease and compensate for limitations [41, 131]. The present studies can not provide answers if causality exists in these aspects. We do not know if the individuals had a low PA level because of low physical capacity [70], or were incapable of utilizing their capacity because of anxiety or fear, heavy breathing [46], low health or low quality of life. However, it can be shown that the level of physical activity is not enough to maintain health according to worldwide recommendations [74].

Generally promoting physical activity in the population could make subjects more aware of a developing disease. In a Position Stand on “Exercise and Physical Activity for Older Adults” (2009) [72], physical activity was recommended as a therapeutic intervention for COPD (among many other chronic diseases), with a specification of its therapeutic role in COPD “for extrapulmonary manifestations”. Watz et al [132] investigated relationships between pulmonary and extrapulmonary factors and reduced physical activity and, though a large number of factors including lifestyle confounders were included, these could explain less than 50% of the total physical activity variance. This indicates that factors such as lung hyperinflation, diastolic left heart dysfunction and systemic inflammation are important and perhaps open to therapeutic intervention [133]. In Sweden, the possibility of using the manual “FYSS” (Physical Activity in the Prevention and Treatment of Disease) [134], has only been utilized to a limited extent, although increasing during the last years. Leijon et al [135] reported that, among prescriptions of physical activity (physical activity referral), less than one percent of the referrals were due to COPD.

There is convincing evidence that PR improves exercise endurance, dyspnoea, functional capacity, and quality of life. The effects of PR are stronger than for almost any other therapy in COPD, and the success also stems from
its favourable influence on systemic effects and comorbidities associated with chronic lung disease [51].

**Spirometry**

For the individual, spirometry of good quality is important for ruling out COPD as a diagnosis where there is no airflow limitation but where a differential diagnosis is possible [3].

The results emphasize the importance of high quality spirometry in all settings. Educational activities such as a “spirometry driving license” are ongoing in many countries. It is important to have a high minimum level of quality both in performance and interpretation of results, not to label persons with incorrect diagnoses and perhaps causing stigmatisation and consequences for the individual and surrounding people.

**Future aspects**

Previous studies have often focused on risk factors and negative influences on health. The new positive outlook for COPD as a preventable and treatable disease is an interesting background to this thesis, where health professionals with an open attitude hopefully can provide support to the individual with COPD in the early diagnostic process. Providing opportunities for pulmonary rehabilitation based on the patient’s individual needs are important, and to investigate causal effects of promoting physical activity in COPD with its associations to good health and quality of life are issues for future research.
Conclusions

- “Consequences of smoking” can be a major impact and “Restrictions in physical activity” a key indicator of evolving disease.
- Shame can be an obstacle in the diagnostic process for patients with COPD and can hinder them from seeking help and communicating about the symptoms of emerging disease to health professionals as well as family and friends.
- Low levels of physical activity and impaired health related quality of life were common among subjects with COPD or RA.
- Fatigue was a prominent symptom experienced by half of the subjects with COPD or RA.
- Subjects with COPD or RA require special attention concerning physical activity, depressive symptoms and symptoms of fatigue.
- The new paradigm of change in lifestyle behaviour and focus on prevention can be important to adopt in connection with chronic diseases.
- Self-rated good health status and quality of life were associated with higher levels of physical activity in subjects with COPD.
- Promotion of physical activity can be important to maintain or improve health and quality of life in subjects with COPD.
- In clinical practice, 30% of patients with a new diagnosis of COPD, had spirometry data in medical records confirming the diagnosis.
- Attention to the quality of spirometry measurements and interpretation of the results are needed to correctly diagnose patients with COPD.
Swedish summary

Kroniskt obstruktiv lungsjukdom (KOL) är den femte vanligaste dödsorsaken i världen och kommer enligt WHO att år 2020 vara den tredje vanligaste. I Sverige beräknas mellan 400 000 och 700 000 personer ha KOL. Sjukdomen är ovanlig före 40 års ålder, men ökar med stigande ålder. Sjukvårdskonsumtion bland patienter med KOL är hög, såväl inom sjukhus- som inom primärvård.

KOL är en långsamt progredierande inflammatorisk lungsjukdom som kännetecknas av kronisk luftvägsobstruktion. Diagnosen bekräftas med spirometri. KOL betraktas också som en systemsjukdom, eftersom den påverkar flera organ och organsystem i kroppen. Fysisk inaktivitet är vanlig hos personer med KOL bland annat på grund av ökad andfåddhet och svag benmuskulatur. Fysisk inaktivitet tillsammans med trötthet och andra samtidiga sjukdomar kan medföra att personen hamnar i en ond spiral med sämre funktionsförmåga, social isolering och sänkt livskvalitet.

Syfte

Syftet med avhandlingen var att beskriva personer med KOL ur olika perspektiv. Fokus var att (1) studera patientens perspektiv vid tidpunkt för diagnos, (2) jämföra olika kroniska sjukdomars påverkan på fysisk aktivitetsnivå och livskvalitet, (3) identifiera faktorer av betydelse för god hälsa och livskvalitet och (4) undersöka diagnostisk spirometri i klinisk verksamhet.

Delarbete I

Första delarbetet beskriver personer i primärvården (n=10) som nyligen fått diagnosen KOL eller varit under utredning. En kvalitativ metod, grounded theory, användes och data samlades in via intervjuer och analyserades. Resultaten redovisas i en modell där ”Konsekvenser av rökning” var kärnkategorin. Under analysen framträdde kategorin ”Skam” som en huvudkategori, som påverkade andra kategorier under förloppet. Begränsningar i fysisk aktivitet var en indikator för att sjukdomen höll på att utvecklas och att få en diagnos var väsentligt för patienten. En slutsats var att det är viktigt att man i sjukvården uppmärksammar personer som riskerar att utveckla KOL och har en öppen och inte fördömande attityd, eftersom skam kan hindra personer från att söka sjukvård. Vidare upplevs det viktigt för patienten att få en tydlig diagnos.
Delarbete II och III

Delarbete II och III utgick från befolkningsenkäten ”Liv och hälsa”, som genomförs var fjärde år i landstingen i Sörmlands, Uppsala, Värmlands, Västmanlands och Örebro län.

I delarbete II analyserades data från Liv och hälsa 2004, där fysisk aktivitet och livskvalitet jämfördes hos personer (40–84 år) med de kroniska sjukdomarna KOL, reumatoid artrit (RA) och diabetes mellitus (DM) samt friska kontroller (n=10 755). Resultaten visade att den fysiska aktiviteten var på en nivå som, enligt rekommendationer, inte är tillräcklig för att bibehålla en god hälsa. Andelen som inte hade en tillräckligt hög nivå var: KOL (84%), RA (74%), DM (72%) och kontroller (60%) (p<0.001 KOL vs RA, DM och kontroller). Livskvalitet mätt med EQ-5D (EuroQoL 5 dimensioners formulär) var sämst hos personer med KOL eller RA. Trötthet upplevdes av hälften av patienterna med KOL eller RA. En slutsats är att fysisk inaktivitet behöver uppmärksammas hos personer med kroniska sjukdomar.


Delarbete IV

Delarbete IV utgick ifrån Praxisstudien i Uppsala-Örebroregionen. Slumpvis utvalda patienter från 56 vårdcentraler och öppenvårdsmottagningar på 14 sjukhus inkluderades i studien. Spirometridata från de patienter som fått KOL-diagnos under studieperioden (2000-2003, n=533) inkluderades. Diagnostisk spirometri definierades som spirometri utförd inom 6 månader före eller efter diagnosdatum. Resultatet visade att spirometridata saknades hos 41% av patienterna och hos ytterligare 14% saknades värden efter bronkdilatation. Trettio procent av det totala antalet patienter hade värden efter bronkdilatation under 0.70 för kvoten FEV₁/VC (forcerad expiratorisk volym under första sekunden / vitalkapacitet), dvs. var obstruktiva. Hos 15% var kvoten FEV₁/VC ≥ 0.70, dvs. var inte obstruktiva. Utmärkande för dessa var låg ålder, kvinnligt kön, rökning, högt BMI och kortare tid för forcerad ut-
andning. Utandningstid var den kvalitetsparameter som oftast inte var uppfyld. Slutsatser var att hos endast en tredjedel av patienterna med nydiagnostiserad KOL kunde diagnos bekräftas av spirometridata i journal. Att ha tillgång till spirometriapparatur är inte tillräckligt, utan den måste användas med god kvalitet enligt riktlinjer. Ej fullständig utandning mått som utandningstid var den faktor som oftast påverkade kvaliteten på spirometriundersökningen.

Sammanfattning

Den positiva framtidssynen på KOL som en sjukdom möjlig att förebygga och behandla är en god grund för denna avhandling. Förhoppningsvis kan behandlande personal med en öppen attityd stödja personer, där KOL håller på att diagnostiseras. Att också ge möjligheter till individanpassad rehabilitering är väsentligt. Fortsatt forskning behövs för att undersöka eventuella orsakssamband mellan ökad fysisk aktivitet och förbättrad hälsa och livskvalitet för patienter med KOL.
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