Management of patients with COPD in Primary Health Care
”Det är stoltare våga sitt tärningskast, än tyna med slocknande låge, det är skönare lyss till en sträng som brast, än att aldrig spänna en båge”
(Ur ”Åkallan och löfte” av Verner von Heidenstam, 1859–1940)
Management of patients with Chronic Obstructive Pulmonary Disease in Primary Health Care

A study of a nurse-led multidisciplinary programme of pulmonary rehabilitation
Abstract


The aim of this thesis was to modify and evaluate effects, as well as to describe experiences of a nurse-led multidisciplinary programme of pulmonary rehabilitation in primary health care for patients with chronic obstructive pulmonary disease (COPD) and their next of kin.

Interviews were performed with 12 COPD nurses about their experiences of patient education (I). Forty-nine patients participated in the intervention group and 54 in the control group in a quasi-experimental study which investigated the effects of the programme on functional capacity, quality of life and exacerbation frequency during one year (II). Interviews were performed related to the experiences of 20 patients who had participated in the six-week programme (III) and the experiences of 20 next of kin to the patients that had participated (IV).

The results showed that COPD nurses fluctuated between security and insecurity in patient education and were in need of support, time, structure and collaboration to develop their patient education (I). In Study II there were no differences between the groups with regard to functional capacity and quality of life, but the number of exacerbations decreased in the intervention group and increased in the control group (II). The patients in study III had allowed themselves to live at their own pace following the programme but a constant fear was present in spite of the programme (III). Next of kin in Study IV had a life that remained overshadowed by illness but there were positive outcomes of the programme as long as two years afterwards. The next of kin also had constant fear, however (IV).

In conclusion, the six week programme brought about results in changing everyday life. Nevertheless, all lived in the shadow of fear and uncertainty in spite of the programme. More research is needed to address the requirements of COPD nurses, patients and next of kin.

Keywords: COPD, exacerbations, experiences, functional capacity, next of kin, nursing care, primary care, quality of life.

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LIST OF PUBLICATIONS

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III. Zakrisson AB, Theander K, Anderzén Carlsson A. Experiences among patients with COPD one year after attending a primary care nurse-led multidisciplinary programme. Submitted for publication.

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LIST OF ABBREVIATIONS

ACN  Asthma/COPD Nurse
ACC  Asthma/COPD Clinics
CCQ  Clinical COPD Questionnaire
COPD Chronic Obstructive Pulmonary Disease
FEV₁ Forced Expiratory Volume in first second
FVC  Forced Vital Capacity
GOLD Global Initiative for Chronic Obstructive Lung Disease
HRQoL Health Related Quality of Life
MI   Motivational Interview
NMP  Nurse-led Multidisciplinary Programme
PHC  Primary Health Care
PR   Pulmonary rehabilitation
QoL  Quality of Life
6MWT 6-Minutes Walking Test
SGRQ St. George’s Respiratory Questionnaire
TTM  Transtheoretical Model
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Prolog
Brev sänt till en av distriktsköterskorna på en av de deltagande vårdcentrarna.
Svenska

Örebro 080618

Bästa sjuksyster!

Jag lovade i våras, på ditt önskemål, att skriva ned min uppfattning av mina erfarenheter av KOL-programmet som jag deltog i genom vårdcentralens försorg. Det har gått en tid sedan dess, vilket kan vara nytigt innan intrrycken summeras. Sjukdomsuppfattningen har mognat och står i tydligare relation till den omfattande informationen. Jag delar upp mina synpunkter i en personlig upplevelse av programmet jag deltog i, och några generella synpunkter i största allmänhet om information vårdgivare/patient.

PERSONLIG UPPFATTNING OM PROGRAMMET VID ER VÅRDCENTRAL
Mycket trivsamma former som, med antiseptisk befrielse från moraliserande undertoner, förmedlade insikter som idag betydligt underlättar tillvaron. Erfarenheter som, i begränsad utsträckning, omedvetet förvärvats tidigare fann stöd och utvecklades till mera fasta kunskaper som idag kan användas medvetet. T.ex. att mental förberedelse med aktiv påbörjad djupandning med långsam utandning inför ett ansträngande moment – underlättar påtagligt. Alltså, ungefär som sprinter löparna inför sina 100-meterslopp.

Förutom rökning bör också trötthet och en mängd ”giftfria” psykosociala omständigheter beaktas vid andningssvårigheter. Sömnens betydelse har i detta sammanhang fått en ny dimension. En annan betydelsefull insikt med direkt funktion är möjligheten – att reducera slembildning med minskat intag av mjölkprodukter. Också ”huffning” istället för hostning har varit direkt värdefull.

GENERELLA SYNPUNKTER PÅ INFORMATION VÅRDGIVARE/PATIENT
"Diagnos" är vårdgivarens slutsats av en undersökning – och utgångsläge för ev. behandling. Patienten kan däremot många gånger endast ha glädje av diagnosen – om denna är hygieniskt (eller socialt) gångbar som t. ex.

Med vänlig hälsning

Willy Jansson¹

PS: Har en uppsättning Atrovent som skrevs ut till mig för ett antal år sedan och nu visat sig mycket effektiv – trots att ”bäst-före-datum” passerats med god marginal. Då jag är mycket nöjd med resultatet hoppas jag att denna – vid behov - kan skrivas ut på nytt. DS

Publicerad med tillåtelse av deltagaren.
Prologue
A letter sent to a COPD nurse at one of the participating primary health care centres.

English

Örebro 080618

Dear nurse,

In accordance with your request I have written down my perceptions of the programme, my participation in which was arranged by the primary care centre. A period of time has elapsed since then, which can facilitate the summing up of one’s impressions. My perception of the illness has matured and become clearer due to the comprehensive information provided. I will divide my views of the programme into my personal experiences and some common points relevant to caregivers/patients in general.

PERSONAL EXPERIENCES OF THE PROGRAMME AT YOUR CARE CENTRE
Insights were provided in a very pleasant environment completely free of moralising undertones, insights that today make life considerably easier. To some extent, previous insights that were unconsciously acquired were confirmed and developed into more robust knowledge that can be used today in a conscious way. For example, the fact that mental preparation with actively initiated deep breathing and slow exhalation before a strenuous action is clearly beneficial. That is, more or less like sprinters prior to a 100 m race.

Besides smoking, tiredness and a large number of ‘non-toxic’ psychosocial circumstances should be taken into consideration in the presence of breathing difficulties. The importance of sleep has become a new dimension in this context. Another valuable insight directly related to function is the possibility of reducing the formation of mucus by limiting the intake of dairy products. In addition, huffing instead of coughing proved valuable.

COMMON POINTS RELEVANT TO CAREGIVERS/PATIENTS IN GENERAL
‘Diagnosis’ is the conclusion of the health care professional’s examination as well as the point of departure for any treatment. However, in many cases patients can benefit from the diagnosis only if it is hygienically (or socially) acceptable, for example as a suitable topic of conversation at the
dinner table. In our case we are dealing with a slow, ‘insidious’ condition that can be very difficult to ‘take in’. Presumably the information programme is aimed at providing patients not with a diagnosis but with an adequate understanding of the condition as a motivation and basis for self-care. It is a very commendable initiative to counteract the ‘gap’ that patients experience between the diagnosis and an adequate personal understanding of the condition. For you that is certainly nothing new – but for the patient it is a distinct ‘Aha experience’.

Although I received my diagnosis 10 years ago, it is only now that I have attained an understanding of my condition.

As a somewhat ‘reluctant patient’ in this connection, I am aware of my own responsibility, which, however, does not prevent me from considering the problem interesting.

With best wishes,

Willy Jansson¹

PS: I have Atrovent, which was prescribed several years ago and, despite having passed its ‘best before date’ by a good margin, is still very effective. As I am very happy with it. I hope that, should the need arise, it can be prescribed again. DS

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INTRODUCTION
When I in the mid-1990s started a nurse-led asthma/COPD clinic in my primary health care (PHC) centre, it functioned just as an asthma clinic. Chronic obstructive pulmonary disease (COPD) was an uncommon diagnosis in PHC at that time. I was frustrated, however, over these seriously ill patients who suffered with breathlessness and were without power, and I thought I had nothing to offer. The patients were grateful nonetheless and seemed to be satisfied, which bewildered me. However, a few years later I passed my examination as an asthma/COPD nurse, a university course, and during that course I found out that there was much that could be done for these patients with COPD through the content in patient education, physical training, dietary advice and so on. Previous reports on the management of COPD came from special clinics in hospital settings. My research question, therefore, was founded on the question, What can we do for patients with COPD in primary health care and, if all this is already known, why do we not do it? There started my journey in the world of research.

BACKGROUND
This doctoral thesis deals with individuals as asthma/COPD nurses, patients with COPD and their next of kin in the context of a nurse-led multidisciplinary programme of pulmonary rehabilitation (PR) in PHC. I will refer to them as nurses, patients and next of kin to avoid misunderstandings. It is worth noting that patients are also persons and individuals, but in this context they are called patients.

Chronic obstructive pulmonary disease
COPD is a leading cause of chronic morbidity world-wide and constitutes a major health problem. It is manifested as chronic obstruction of airways and is a disease characterised by a slowly progressive airflow limitation that is not fully reversible. Pharmacological treatment is seen as limiting the symptoms. COPD cannot be cured, but it is well known that PR has positive effects on patients’ function in everyday life. COPD is caused mainly by tobacco smoking. In Sweden half of the smokers who have reached advanced age have developed COPD, and the population prevalence is 14% for those aged 45 year and over. A systematic review shows that the prevalence of COPD in Europe varies between 2.6% and 26.1%. COPD causes globally almost as many deaths as HIV/AIDS (2.7 million). The World Health Organisation (WHO) anticipates that COPD will be the third cause of death world-wide in the year 2020. In the past more men
COPD is a systemic inflammatory disease leading to increased risk of cardiovascular disease and neurological and musculo-skeletal symptoms. Very severe COPD has additional consequences such as malnutrition, incontinence, osteoporosis and muscle weakness. Later, when chronic breathing failure occurs, it influences the heart, kidneys and blood circulation.

Many patients with COPD have co-morbidities such as cardiovascular disease, stroke, diabetes and depression, and they are at increased risk of malignancy, particularly lung cancer. These co-morbidities are major causes of excess morbidity and mortality in patients with COPD. Because of the co-morbidity it can be suitable that patients with COPD are managed by generalists in PHC in structured programmes.

**Impact of COPD in everyday life**

In its early stages COPD can appear without any symptoms. The first symptoms might be a cough and increased phlegm. The presence of a
cough often precedes airway obstruction. The obstruction gives symptoms such as breathlessness, at first during with physical activity but later, in severe COPD, even during rest\textsuperscript{2}. Breathlessness has been described by patients with COPD as the most distressing and frightening symptom and the one with the most impact on everyday life\textsuperscript{13-23}. Breathlessness has been shown to invade almost every aspect of affected persons’ lives and was described as increasingly challenging and threatening to their current lifestyles. The patients’ disease progression contributed to an increased level of dependence on others and to feelings of poor QoL\textsuperscript{16}. Symptoms that patients with COPD related to breathlessness were cough, activity limitation, no energy/fatigue, less social function and anxiety\textsuperscript{20}. Breathlessness has also been shown to have an impact on sleeping disorders, which was aggravated by feelings of isolation, vulnerability and frustration\textsuperscript{21}. Patients experienced that breathlessness made them stop or scale back activities, and it took more time to do things\textsuperscript{22}. They were limited in performing daily activities such as walking, household maintenance and driving, which caused them to spend most of their time at home\textsuperscript{23}.

COPD affects patients’ functioning in daily life, because of decreased functional capacity\textsuperscript{24}, and their quality of life (QoL)\textsuperscript{25-26}, because of breathlessness, fatigue, cough, exacerbations, nutritional problems, decreased exercise tolerance, anxiety and depression\textsuperscript{27-28}. According to American Thoracic Society/European Respiratory Society (ATS/ERS)\textsuperscript{28}, anxiety, depression and poor motivation also have an impact on symptom perception, leading to impairment of functional capacity. Patients with COPD reported that their psychological health was affected by anxiety and depression\textsuperscript{29-31}. They were not thinking about the future beyond the next day\textsuperscript{18}. Emotions ranging from irritation to depression were found in one study, and these ups and downs were frequently associated with patients’ physical ups and downs\textsuperscript{16}. Patients with COPD experienced a sense of guilt that they have caused the disease themselves because of their smoking\textsuperscript{32}. As a result, patients reported low use of services, including health care, and obstacles to seeking advice\textsuperscript{13,19}. They had strong feelings of shame that made it difficult to seek help in medical health care services\textsuperscript{13}. They also experienced that health care service discredited their symptoms\textsuperscript{19}. Patients expressed that they were disappointed with medical health care and that their contact was postponed until they reached a crisis point\textsuperscript{18}. This is important to take into account when patients are recommended to seek early help in case of exacerbations\textsuperscript{2,33-34}.

One study has reported that higher levels of fear related to breathlessness were associated with reduced functional capacity and health-related quality of life (HRQoL)\textsuperscript{35}. Functional capacity has been described by
Exacerbations are frequently caused by respiratory infections and are characterised by deterioration with increased breathlessness and aggravated cough, increased phlegm production and increased difficulties in coughing. An exacerbation is defined as having occurred when the patient characterised by deterioration with increased breathlessness and aggravated cough, increased phlegm production and increased difficulties in daily life. Exacerbations are negative for the patient and have a serious impact on morbidity and mortality. Severe exacerbations requiring hospitalisation are one of the major causes of death in COPD. In a recent meta-analysis the case-fatality rate was estimated to be 15.6% in the overall weighted mean value in COPD whereas the average hospital mortality was 6.7%. Greater frequency of exacerbations accelerates the disease progression. A patient with COPD has 0.6 to 3.5 exacerbations per year on average, and the recovery takes a long time, up to three months. It is therefore important to reduce the number of exacerbations in patients with COPD to slow down the disease progression.
In one study, however, patients were found to be experts on their lives, and they learned how to handle life based on their experience and knowledge as well as integrate the illness and its symptoms into their lives. They used self-talk, relaxation and positive attitudes to reduce psychological distress and promote emotional health. One way of gaining control was by changing activities due to breathlessness, focus on what they enjoyed rather than what they felt the loss of, using support from others and acting normally\textsuperscript{15}. Patients’ experience of living with COPD has been investigated, but deeper knowledge is needed to improve the situation as many patients are managed in PHC.

**Quality of Life**

Patients with chronic diseases, among them COPD, have been reported as having less possibility for a satisfactory QoL than people without a chronic disease\textsuperscript{25-26}. In general, QoL is described as a way of wellbeing perceived by the individual. It is a wide-ranging concept influenced in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of their environment\textsuperscript{49}. Health-related quality of life (HRQoL) has been described as the degree to which a person’s health status affects their self-determined evaluation of satisfaction, or QoL\textsuperscript{50}. The concept of QoL is more comprehensive than HRQoL, including the feature of the environment, which may or may not be affected by health or treatment\textsuperscript{50}. In relation to COPD, HRQoL can be seen as signifying the gap between desires and achievements that is specifically due to the disease\textsuperscript{51}. In WHO’s disability weights for diseases and conditions, disability-adjusted life years (DALY)\textsuperscript{52}, assessed in terms of HRQoL, COPD in stages 1 and 2 is weighted to 0.170 and in stage 3 and 4, to 0.530, where no disability is 0 and full disability is 1. DALY can be related to other chronic diseases such as asthma (0.043), congestive heart failure (0.201) and diabetes mellitus (0.015). In patients with COPD factors like exacerbations, chronic cough, breathlessness and fatigue determine HRQoL\textsuperscript{27,41}.

HRQoL can be assessed by several instruments, and the most common in COPD research is the St. George Respiratory Questionnaire (SGRQ), which is disease specific and involves 51 questions\textsuperscript{53}. Another one is the Clinical COPD Questionnaire (CCQ), which has an advantage of involving only 10 questions\textsuperscript{54} and correlates well with SGRQ\textsuperscript{55}. CCQ has been used in recent studies\textsuperscript{55-58} that have shown that patients with COPD have a lower HRQoL when the disease is associated with heart disease, depression and underweight\textsuperscript{59}. Furthermore, exacerbations have a negative impact on patients’ HRQoL\textsuperscript{55}. COPD affects HRQoL in that patients’ participation in
Managing COPD in primary health care

Next of kin experience of COPD

Next of kin are affected by living with a patient with COPD\textsuperscript{59-66}. They can experience a combination of loss and additional responsibility, often with a lack of social support\textsuperscript{65-66}, and have mediated feelings such as chaos and resignation\textsuperscript{64}. Sleep disorders have also been reported\textsuperscript{59}. Living with a patient with COPD imposed an increasing physical and emotional burden for next of kin, especially the female next of kin, who experienced greater stress in comparison to men\textsuperscript{65}. They felt more confused, anxious and vulnerable compared to men and adopted an approach of “one day at a time” to handle their lives\textsuperscript{66}. Another approach adopted by next of kin was to continue working instead of retiring and to get away and have their own things to do\textsuperscript{62}.

Next of kin have described that the patient’s illness can influence the couple’s communication ability and their closeness together with their common friendship. Female patients with COPD can experience distress at their inability to carry out everyday life, which could lead to relational problems\textsuperscript{65}. Many next of kin felt that they had lost their freedom because they had to give up recreation and social activities. Next of kin experienced not having time to care for their own health\textsuperscript{59}. They felt fear as to whether there would come time when they could not care for the patient or if it would be at the expense of their own health. Some consciously and proactively took care of their own health, however, which enabled them to take care of the patient at home\textsuperscript{63}.

Next of kin have expressed an acceptance of the situation as a “way of life” rather than an “illness” that disturbed life. They saw the situation as a health problem, a lifestyle that has become familiar over many years\textsuperscript{64}. Positive aspects that have been highlighted regarding being a care-giver as a next of kin have been a feeling of satisfaction when they could make things easier for the ill patient and help her/him to stay at home as long as possible and not go for hospital care\textsuperscript{59}. The caring could also be seen as a shared responsibility with the patient that enhanced their relationship\textsuperscript{63}.

Next of kin expressed that they wanted more support from health and medical services, in particular more information and education about COPD\textsuperscript{59, 65} and advice on how to be of help to the patient\textsuperscript{60} so that they could better manage their caring role \textsuperscript{61}. In more detail, some wanted more...
knowledge about how to handle the patient’s breathlessness and exacerbations as these were regarded as challenges for next of kin\textsuperscript{63}. One study stated that next of kin have a major impact in helping the patient overcome, or at least manage, anxiety and might also reduce hospitalisations through their contribution of care\textsuperscript{60}.

Most studies have been conducted in hospital settings, although concerning everyday life. However, it seems important to recruit next of kin to patients treated in PHC. It is also important to study whether PHC can improve the health of the next of kin as they also suffer and have been found to be important to the patient.

**Pulmonary rehabilitation**

The aim of PR, according to ATS/ERS, is to reduce symptoms, optimise functional status and increase the patient’s participation in care. PR focuses on physical exercise conducted by a physiotherapist but includes patient education for self-management and lifestyle changes, energy-saving techniques, psychosocial interventions and dietary interventions by a team that includes a physician, nurse, occupational therapist, social worker and dietician\textsuperscript{28}. Others have emphasised the importance of focusing not only on minimising symptoms and improving exercise capacity and QoL, but also on enhancing perceptions of self-efficacy\textsuperscript{67}. PR has been described as a part of an integrated care process and includes support for the patient’s self-management. That means a shift from management by the health care provider and implies structural behavioural change\textsuperscript{68}. It is argued that it is a process that does not end with one PR programme; it also requires reinforcement and follow-up\textsuperscript{68}.

PR can reduce health care costs by stabilising or reversing systemic manifestations of the disease\textsuperscript{28}. In a Cochrane review the author stated that PR reduces hospital admissions and mortality in exacerbations compared with usual community care, i.e. no rehabilitation\textsuperscript{69}. Bourbeau et al. \textsuperscript{68} have discussed, furthermore, that it is important that PR is done for the right reason: to change patients’ behaviour for better disease control and patient outcomes, not to relieve pressure on the health care system. In another Cochrane review involving patients diagnosed with COPD, receiving PR in a hospital setting was found to increase functional capacity and QoL and to decrease exacerbations\textsuperscript{3}. PR has been performed in hospital settings since the mid-1980s in Sweden. Swedish national guidelines for COPD\textsuperscript{70} recommend PR for patients with COPD in GOLD stage 2 and 3. A recent international guideline\textsuperscript{28} states that PR can be valuable for all patients with respiratory symptoms that are associated with limited functional capacity or reduced QoL.
In PHC settings, studies in PR with a multidisciplinary arrangement have, as far as has been found, rarely been published\textsuperscript{71-74}. Interventions have consisted of an integrated disease management programme, including physical exercise three times a week over a period of three months, with the exception of one study\textsuperscript{72} in which no physical activity was involved, as well as education on self-management. The patients in the studies improved their QoL\textsuperscript{71-74}. Exacerbations\textsuperscript{72} and breathlessness were still decreased one year after the programme ended\textsuperscript{71, 73}. Furthermore, participants’ functional capacity increased\textsuperscript{71, 73-74}.

A study concerning only patient education for patients with COPD in PHC showed that it had effect in increased QoL and decreased smoking habits compared to usual care with only pharmacological treatment that had no effect of the patients QoL and smoking habits\textsuperscript{75}, in accordance with studies in hospital settings\textsuperscript{3}. One study comparing a seven-week PR in a PHC setting to PR in a hospital setting showed that improvements in QoL and functional capacity were reasonably similar after three months\textsuperscript{76}. In Finland a 10-year COPD prevention and treatment programme has been set up focusing on multidisciplinary strategies, efficient and effective training and web-based guidelines for use in primary care\textsuperscript{77}. It resulted in significant positive consequences; no further increases in COPD prevalence; reduced smoking prevalence; improved quality of diagnosis, especially in PHC; and reduction in hospitalisations due to COPD and reduced costs\textsuperscript{77}.

It has been argued that structured programmes for COPD care need to be established in PHC\textsuperscript{78}, but access to PR is still limited. Internationally it is estimated that less than 5% of the patients with COPD currently have access to rehabilitation\textsuperscript{79}, but no estimates related to Swedish circumstances are available. PR is quite common in hospital settings, but there might be obstacles for the patient because of the distance from home to the hospital\textsuperscript{28}. Therefore, it is important to set up PR programmes in PHC centres, which patients can access in their immediate surroundings and also where they can be evaluated to find a programme that fits their needs.

The experiences of patients with COPD with PR in hospital settings are described mainly in positive terms. Studies have shown that the group as such was very important because participants experienced support and a sense of belonging when meeting others who were in the same situation\textsuperscript{80-84}. PR provided an opportunity to share problems with and offer advice to others\textsuperscript{80-81}. In some cases, however, patients did not experience any changes, had no motivation and did not have a sense of belonging to the group\textsuperscript{81-82}. Learning self-management was described as valuable, especially relaxation and breathing techniques to manage breathlessness\textsuperscript{80, 82-84}. Participants learned lifestyle changes, were encouraged to engage in physical exercise three times a week over a period of three months, with the exception of one study\textsuperscript{72} in which no physical activity was involved, as well as education on self-management. The patients in the studies improved their QoL\textsuperscript{71-74}. Exacerbations\textsuperscript{72} and breathlessness were still decreased one year after the programme ended\textsuperscript{71, 73}. Furthermore, participants’ functional capacity increased\textsuperscript{71, 73-74}.
training, gained better health and learned how to limit their activities\textsuperscript{80-81, 84}. They felt that they had regained control over their lives and obtained a new identity, that of living with COPD\textsuperscript{81}. One important factor in PR was access to highly competent and committed staff members who showed that they had time for the participants and made them feel secure\textsuperscript{81, 84}. However, there are few studies describing experience of PR in PHC from the patient’s perspective. It can be supposed that next of kin are important for patients outcomes of PR, but no studies were found about the experience of PR from their perspective. It is also important to illuminate their experiences to avoid health problems among next of kin.

**Nurse-led COPD clinics**

In Sweden about 50\% of PHC centres have a nurse-led asthma/COPD clinic\textsuperscript{85} that traditionally conducts investigations for diagnoses with spirometry and provides patient education in both asthma and COPD. Patients with allergies are also involved in the clinic. The Swedish National Board of Health and Welfare\textsuperscript{79} has developed guidelines for the care of asthma/COPD that state that asthma/COPD clinics could be established in PHC. The guidelines set a high priority on patient education\textsuperscript{70}. There are updated criteria with a structure for these nurse-led asthma/COPD clinics\textsuperscript{86}. The optimal criterion is a specialist-educated nurse/RN, currently with postgraduate education in asthma/COPD and working with a physician, a specialist in family medicine who has the medical responsibility for the patient. Equipment is needed for spirometry, pulse-oxymetry and nebulisation. Also needed are regular appointments and telephone consultations with the asthma/COPD nurse; structured investigations involving spirometry, patient education, smoking cessation support and suggestions to patients for follow-ups, and collaboration with a team of physiotherapists, physicians, occupational therapists, dieticians and social workers. The criteria recommend time resource allocations of 1.5 hours up to 4 hours per 1000 citizens per week\textsuperscript{86}. A Cochrane review has found no noticeable differences in care between physicians and nurses in health outcomes for patients, process of care, resource utilisation or cost\textsuperscript{87}. A Swedish study showed that having asthma/COPD clinics with a specialised COPD nurse decreased the patients’ number of exacerbations\textsuperscript{88}.

The structural development of COPD care in Sweden is satisfactory, but treatment is not optimal at all management levels. The allocation of time reached its lowest level of 1.5 hours per 1000 citizens per week in 8\% of the examined PHC centres; the rest were below the recommendations of time resources\textsuperscript{88}. In another study, 70\% of patients with a diagnosis of COPD lacked spirometry results confirming the diagnosis, although 95\%
of the PHC centres had access to a spirometer. In patients with a new COPD diagnosis, spirometry data were available for 59% \(^{89}\), which is slightly higher than in other international studies\(^{90,93}\). Early detection and treatment of acute exacerbations together with written action plans are important in maintaining and enhancing patient care and allow more appropriate use of health care\(^{33,34}\).

Nurse-led COPD clinics in Swedish PHC are, in most cases, runned by a nurse/RN specialising in public health care. Their competence as nurses is as a generalist after one and a half years of specialist education in public health care and at least two years after their examination and working as a registered nurse (RN). Nurses specialising in public health care need the ability to work independently, a scientific attitude, multicultural knowledge and professional responsibility\(^{94}\). Competences include nursing care, public health, medical science, leadership and pedagogy. The pedagogic part is almost the main component in the work\(^{94}\), but PR is not a matter of course for COPD nurses today. They provide almost exclusively individual patient education.

Previous research in patient education regarding COPD has focused on its effects, such as improved functional capacity and QoL and decreased number of exacerbations\(^3\). Studies on nurses’ perceptions or their performance of patient education have a slightly different focuses; for example whether their work is individual oriented, their communication ability and the practice environment\(^{95,97}\). The results showed that the nurses were either task oriented, to do spirometry or show inhaling techniques, or individual oriented. The individual-oriented nurses worked more independently than the task-oriented nurses did and were better able to meet the patients’ individual needs, which are important in patient education. The task-oriented nurses needed more support from management and colleagues so as to be individual oriented\(^{95}\). Another study showed that communication seldom involved patients’ ideas, fears and continuing problems. Most of the consultation time at nurse-led COPD clinics was spent on patients’ medical and physical problems; and on investigations such as spirometry. It was found that nurses rarely planned their consultations on an individual basis. It was also identified that the nurses need help to reflect on how to improve visit structure, self-management, smoking cessation support and patient communication\(^{96}\). In another study nurses working in nurse-led clinics reported that they felt isolated, and they were more likely than other nurses to leave nursing practice within five years. They were also less likely to have someone to discuss clinical/professional problems with because they were alone in their professional practice. Factors contributing to this were generally located within the practice environment\(^{97}\).
There is a lack of studies about the nurses’ perceptions of patient education or how they perform education, which is important to understand when developing the work of the COPD nurse. The structural development of COPD care also needs to be optimised.

**Patient education**

As it was indicated previously, pedagogy is a main component of the work of nurses specialising in public health and thereby the COPD nurses’ contact with patients. Education and pedagogy are not unambiguous concepts, however. Generally, education consists of different components, such as teaching, supervision, information and learning. Individuals’ ability to learn, according to Marton, depends on their previous knowledge and their linguistic attainments together with knowledge as the understanding of content. New insights can arise when there is a meeting between different views of the same phenomena, and learning can take place.

One definition of patient education is provided by Piredda as “a planned process of activities designed to enable people to improve knowledge, to acquire skills and to facilitate voluntary adaptation of behaviours in order to restore, maintain and improve health.” This definition moves from a traditionally teacher-centred to a patient-centred approach to promote individualisation in care. In terms of patient education, the concept of enablement can describe the process between the patient and the nurse. Through enablement the patient can be assisted in acquiring or expending means, abilities and/or opportunities to complete a task or fulfil a role.

Patient education is meant to lead to, among other things, self-management/self-care and self-efficacy. An assumption in patient education is that it does not only mean conveying facts; it also has an emotional component involving how to handle feelings and reactions. Education, both written and verbal, on self-management has been described as helping patients gain the motivation, skills and confidence to control their disease. The patient needs to learn to integrate these self-management skills into everyday life. Furthermore, according to Bourbeau, these self-management skills include resource utilisation, patient-provider relationships, problem solving, decision making, early symptom recognition and taking action based on a predefined action plan. Orem describes nursing treatment as complementing medical treatment and teaching as a helping method requiring that the nurse know thoroughly what the patient to be helped needs to know.
Self-efficacy has been defined by Bandura\textsuperscript{109} as follows: “Perceived self-efficacy refers to beliefs in one’s capabilities to organise and execute the courses of action required to produce given attainment”. The nurse’s role is to influence patients’ choice of activities and their motivational level to change an unwanted behaviour. Functioning effectively requires both skills and efficacy beliefs, and the nurse may support patients in gaining confidence that they can act to take some control over potential threats or stressors\textsuperscript{109}.

Meaning and understanding for the patient, it is argued, is a central matter\textsuperscript{102}. Even if individuals memorise information well, they will not necessarily be able to put the information to use\textsuperscript{110}. Regular contact with the same health care professional, control over stimuli that trigger the disease severity and rewards for progress, establishment of a system for aiding the memory and self-care rituals are seen as among the more successful interventions\textsuperscript{110}. Coaching, according to Hayes et al.\textsuperscript{111}, can be used to inspire and help patients to learn. It can be effective in encouraging, inspiring and empowering patients to reach their maximum health potential when lifestyle changes are required. Coaching focuses on the patient’s feelings, desires, experiences, personal goals, discovery and learning; it focuses on who the person is\textsuperscript{111}. Listening is central in the coaching process, and by listening, the coach learns what is important to the patient. Coaching involves ongoing support, regular sessions, patient-set goals, trust, honesty and respect\textsuperscript{111}.

**Patient education in COPD**

As has been the situation for many years, nurses who are working today as COPD nurses have in their education no or, at most, sparing education in pedagogy. In their education major emphasis was placed on the content of learning, “what” had to be learned rather than “how” learning could take place, as Marton also discussed as a traditional form of pedagogy\textsuperscript{102}.

Nursing care in COPD involves motivating patients to change their lifestyle, helping them to adapt their existence to a fairly good life and educating them about COPD\textsuperscript{112}. It is argued that education for patients with COPD is important for two reasons: first, to allow patients to understand how the disease affects them and, second, to help them understand the strategies available to manage their disease\textsuperscript{113}. One Cochrane review states that patient education seems to be valuable in restoring, maintaining and improving health but they cannot yet formulate recommendations regarding the effectiveness of education for patients with COPD\textsuperscript{114}.

Nurse-led individual patient education in COPD has been investigated. One study showed increased disease-specific knowledge after only two
hours of education in topics as pathophysiology, symptoms and what makes them worse, the importance of and strategies for smoking cessation, respiratory medications, symptoms of an emergent exacerbation and the role of regular exercise. In another study the number of patients that stopped smoking increased and their knowledge about the disease and their QoL were improved by structured self-management education and smoking cessation. In a Cochrane review self-management education appeared to be associated with a reduction in hospital admissions. The studies in the Cochrane review, and also others on the topic of PR, described the content of patient education sparsely, however. This needs to be clarified in further studies.

Teamwork is important in the care of COPD when the patients suffer from co-morbidities. Multidisciplinary teams are used especially in fields where patients’ need for care is extensive and complex, such as COPD. Within the team professionals with competence in different fields satisfy the patient's physical, psychological and social needs, including by patient education. Combining various disciplines in an integrated model has been shown to improve care processes and patient outcomes in PHC for COPD. One important task for the nurse-led clinic and its team is to help patients stop smoking. The patient with COPD must stop smoking to slow down the progression of the disease, preferably in its early stages or, of course, for all smokers before they have COPD.
RATIONALE OF THE THESIS

It is well known that PR can reduce exacerbations and increase functional capacity and HRQoL with improved function in everyday life in patients with COPD in hospital settings, but PR has not been adequately investigated in PHC. The question remains if PR in PHC can reduce exacerbations and increase functional capacity and HRQoL. Patient education is one of the main components of PR. Studies of COPD nurses’ patient education for patients with COPD have shown that the nurses need more education in the provision of individual-oriented education and to improve their communication ability. They also experience loneliness in their practice environment. Deeper knowledge is required to support the nurses’ development in patient education and coaching. Patients’ experience of PR in a hospital setting was that learning self-management was valuable, and they felt that they had regained control over their lives. There is a lack of studies of patients’ experiences of PR in PHC, however, and this is needed for further development of PR programmes in PHC. Furthermore, next of kin experience a heavy burden in life together with a patient suffering from COPD. No knowledge is available on how PR affects next of kin, and more research is needed to support them and to avoid their eventual health problems.
AIMS

The overall aim in this doctoral thesis was to modify and evaluate the effects as well as to describe the experiences in a nurse-led multidisciplinary programme of pulmonary rehabilitation in primary health care for patients with COPD and their next of kin.

To achieve the overall aim, studies were conducted with the following aims:

- To describe asthma/COPD nurses’ experience of educating patients with COPD in primary health care (Study I).
- To investigate the effects of a nurse-led multidisciplinary programme, incorporating pulmonary rehabilitation, in a primary health care setting on functional capacity, HRQoL and exacerbations in patients with COPD (Study II).
- To describe experiences among patients with COPD of participating in a nurse-led multidisciplinary programme of pulmonary rehabilitation in a primary health care setting, one year after completion (Study III).
- To describe next of kin’s experience of living with a patient suffering from COPD, two years after the latter’s participation in a primary care nurse-led multidisciplinary programme of pulmonary rehabilitation (Study IV).

MATERIALS AND METHODS

Design

This doctoral thesis is based on four separate data-gathering procedures. Three are based on qualitative semi-structured interviews (I, III and IV), and one is an intervention, a quasi-experimental study (II) (Table 2). The studies were performed between the years 2005 and 2010 in PHC centres in two county councils in Sweden.

Studies I, III and IV have a descriptive qualitative design. A qualitative design was chosen to gain understanding of nurses’ experience of providing education to patients with COPD (I), and patients’ (III) and next of kin’s (IV) experiences in a nurse-led multidisciplinary rehabilitation programme. Qualitative design is a science that explores to a deeper understanding rather than giving an account. With respect to ontology, qualitative design is rooted in humanistic thinking. The ontological reality in a qualitative approach means an understanding of the individual as a whole. The knowledge derives from the participants’ experiences. Epistemologically, the inquirer interacts with those being researched: nurses, patients and next of kin. Findings are a construction of the interactive process.
Study II has a quasi-experimental, longitudinal design over one year that compared one intervention group and one control group. A quasi-experimental design was chosen in order to investigate the effects of the nurse-led multidisciplinary programme in PHC. Primary outcomes were functional capacity, HRQoL and number of exacerbations in patients with COPD (II). Quasi-experimental studies are characterised by a positivistic approach with a quantitative design, numeric information and statistical procedures used in the analysis. The ontological assumption of positivism is that reality can be studied and known; there is a real world driven by real natural causes. Quasi-experimental design is used when there lacks randomisation to treatment groups, and when the researcher cannot be sure about the given treatment in the control group (“usual care”), in comparison to randomised controlled trials where a higher degree of control is possible. The strength of a quasi-experimental design is that there exists a comparison between two groups in comparison to pre-post-test research. Ontologically, the approach is to see the individual parts rather than the entirety. Epistemologically, the researcher strives to be as objective as possible, and the findings of measurements should not be influenced.

### Table 2. Overview of study designs and research methodologies

<table>
<thead>
<tr>
<th>Paper</th>
<th>Design</th>
<th>Participants</th>
<th>Data collection</th>
<th>Data analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Descriptive qualitative</td>
<td>12 COPD nurses</td>
<td>Semi-structured interviews</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>II</td>
<td>Quasi-experimental, longitudinal during one year</td>
<td>49 patients in intervention group, 54 patients in control group</td>
<td>Functional capacity – 6MWT, HRQoL – CCQ, Exacerbations calculated through patient records</td>
<td>Independent t-tests, paired sample t-tests, Mann-Whitney U test, Wilcoxon signed-rank test</td>
</tr>
<tr>
<td>III</td>
<td>Descriptive qualitative</td>
<td>20 patients</td>
<td>Semi-structured interviews</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>Descriptive qualitative</td>
<td>20 next of kin</td>
<td>Semi-structured interviews</td>
<td>Qualitative content analysis</td>
</tr>
</tbody>
</table>

Intervention
A pilot study was performed over eight weeks in 2004, involving one meeting every second week at the author’s PHC centre. In this doctoral thesis, a modified, yet standardised, PR programme was conducted. This entailed a nurse-led multidisciplinary programme for six weeks with one meeting of
two hours each week for patients with COPD and next of kin invited to one session. It was modified from guidelines\textsuperscript{2, 28} by that it was conducted in another setting than hospital, another constitution of the team and in response to the results of the COPD nurses’ experience of patient education in Study I. There was no dietician employed in PHC who could provide dietary advice. Furthermore, no opportunities for physical training existed to the extent recommended in the guidelines\textsuperscript{28}; namely supervised training three times a week for at least two months, preferably with access to oxygen. At the prospect of the intervention in Study II, it was taken into account that the results in Study I showed that the nurses wanted access to more education about COPD, more time, more structure and more collaboration with the other professionals, needs that were met within the programme. To standardise the nurse-led multidisciplinary programme, all team members at all nine PHC centres included in the study received education, arranged by the author and a team familiar with PR, about COPD and the study design for one day before the study started. The COPD nurse was given half a day of training in assessments and nutrition advice by the author and a nurse specialising in nutrition in COPD. The outline of the nurse-led multidisciplinary programme is displayed in Table 3.

### Table 3. The six-week nurse-led multidisciplinary programme

<table>
<thead>
<tr>
<th>Meeting 1</th>
<th>Meeting 2</th>
<th>Meeting 3</th>
<th>Meeting 4</th>
<th>Meeting 5</th>
<th>Meeting 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease and medication, anatomy and physiology</td>
<td>Physical activity, theory</td>
<td>Nutrition advice</td>
<td>Energy conservation</td>
<td>Anxiety and stress management</td>
<td>Condensed information of all topics to next of kin</td>
</tr>
<tr>
<td>COPD nurse and physician</td>
<td>Physiotherapist</td>
<td>COPD nurse</td>
<td>Occupational therapist</td>
<td>Social worker</td>
<td>All professionals</td>
</tr>
<tr>
<td><strong>Physical activity by the physiotherapist</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Including muscle strengthening, aerobic fitness, breathing and coughing techniques, relaxation techniques and home training programme</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The education programme for patients and next of kin derived from authorised guidelines\textsuperscript{2, 28, 70, 122-123} and was used by the teams at all PHC centres. The COPD nurse participated as a group leader in every session, and stop smoking advice was given throughout the whole programme. An individual home training programme was offered to each patient by the physiotherapist.
Below participants, sampling and settings will be described for each study, followed by data collection and data analyses (Studies I-IV).

**COPD nurses’ experience of patient education (I)**

**Participants, sampling and setting**
Asthma/COPD nurses from 21 PHC centres from one county council in central Sweden were invited by an information letter to participate in the interview study in order to map out their needs before the nurse-led multidisciplinary programme began. Twelve nurses from twelve PHC centres agreed to participate (Table 4). Nine declined participation because of lack of time (n=2) and because their current positions involved little patient education (n=3). Four nurses did not respond.

**Table 4. Demographics for COPD nurses (n=12)**

<table>
<thead>
<tr>
<th>Background variable</th>
<th>Number (n)</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educated as RN specialist in public health care at the university level</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RN with asthma/COPD course at the university level</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years as RN</td>
<td>12</td>
<td>28 years</td>
<td>9–41 years</td>
</tr>
<tr>
<td>Years worked in PHC</td>
<td>12</td>
<td>13 years</td>
<td>2–28 years</td>
</tr>
<tr>
<td>Years with asthma/COPD clinic</td>
<td>12</td>
<td>7 years</td>
<td>0.5–12 years</td>
</tr>
<tr>
<td>Hours per week in asthma/COPD clinic</td>
<td>11*</td>
<td>8 hours</td>
<td>2–12 hours</td>
</tr>
<tr>
<td>Patients with COPD per week</td>
<td>12</td>
<td>3 patients</td>
<td>1–6 patients</td>
</tr>
</tbody>
</table>

* One nurse stated “as needed.”

**Data collection**
Semi-structured qualitative interviews were performed by the author during 2005 in a location chosen by the nurse. The interviews focused on the nurses’ experience of educating patients with COPD and lasted 20 to 30 minutes. An interview guide with semi-structured questions was used. This contained three main questions: “How do you experience the meeting with the patient?”, “How do you experience the education?” and “How do you want to develop your patient education?” The narratives was followed up with questions such as, “What do you mean?”, “Can you tell me more?” or “How did you handle the situation?” Individual follow-up questions depended on what emerged during the interview. The interviews were tape-recorded and transcribed verbatim by the author. A pilot interview was conducted to test the questions’ usefulness. They were found to be
acceptable, so no changes were made. That interview is included in the findings.

Effects of a nurse-led multidisciplinary programme of pulmonary rehabilitation (II)

Estimation of sample size
Before the study, no data concerning HRQoL or assessment with CCQ in PHC were available to calculate the study sample size. Results from a pilot study of PR performed by the author in PHC were used, and from the data it was assumed that about 75% of the patients in the intervention group and 20% in the control group should improve their HRQoL. In the present study, the number of patients needed with a power of 80% and with a significance level of 0.05 was then calculated to be about 20 patients in each group. To compensate for potential dropouts, the study was planned to include 50 patients in each group, a total of 100 patients, because these patients are vulnerable and it is known that they drop out of research studies for medical reasons.

Participants, sampling and setting
The inclusion criteria applied to both the intervention group and the control group: patients with COPD diagnosed for at least one year with FEV₁/FVC < 70% and FEV₁ 40% to 59% of predicted, representing GOLD stages 2 and 3. They also had to understand and be able to express themselves in the Swedish language. Pulmonary function tests had been performed within one year of study inclusion. Exclusion criteria were cognitive impairment, substance abuse, severe psychological disease, malignancy or participation in another study.

A total of 49 patients were recruited to the intervention group and 54 in the control group, retrieved from the patient administrative system (Figure 1).

For the recruitment intervention group (n=49), 29 PHC centres with asthma/COPD clinic in two county councils, 21 and eight respectively, were invited to participate. Nine PHC centres accepted to participate in the study, six from one county council and three from the other, and their patients constituted the intervention group. The patients were searched for in the patient administrative system by the nurses at the PHC centres. Twenty PHC centres declined to participate when they had difficulties in building teams. The participating PHC centres were located in both urban and rural areas, and the patients in their catchment areas are living in immediate surroundings. Demographic data are shown in Table 5.
For the recruitment control group (n=54), PHC centres in one of the county council’s (n=15), which had declined to participate as an intervention centre, were invited to participate as control centres, and their patients constituted the control group. They were searched in the patient administrative system by the author. These patients received usual care; i.e. no teamwork, no structured programme and just individual consultations. Demographic data are shown in Table 5.

Table 5. Baseline characteristics of intervention versus control group

<table>
<thead>
<tr>
<th></th>
<th>Intervention (n=49)</th>
<th>Control (n=54)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean (SD)</td>
<td>n</td>
</tr>
<tr>
<td>Male/Female</td>
<td>25/24</td>
<td>32/22</td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td>16</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>67 (4)</td>
<td>68 (5)</td>
<td>0.373</td>
</tr>
<tr>
<td>FEV₁, % predicted</td>
<td>49 (8)</td>
<td>49 (8)</td>
<td>0.966</td>
</tr>
<tr>
<td>BMI</td>
<td>28 (6)</td>
<td>27 (6)</td>
<td>0.576</td>
</tr>
<tr>
<td>6MWT (metres)</td>
<td>391 (89)</td>
<td>360 (88)</td>
<td>0.114</td>
</tr>
<tr>
<td>CCQ, 0-6</td>
<td>2 (1)</td>
<td>2 (1)</td>
<td>0.651</td>
</tr>
<tr>
<td>Exacerbations (n)</td>
<td>0.8 (1.2)</td>
<td>0.4 (1.1)</td>
<td>0.146</td>
</tr>
</tbody>
</table>
For the recruitment control group (n=54), PHC centers in one of the county council’s (n=15), which had declined to participate as an intervention center, were invited to participate as control centers, and their patients constituted the control group. They were searched in the patient administrative system by the author. These patients received usual care; i.e., no teamwork, no structured program and just individual consultations.

Demographic data are shown in Table 5.

### Table 5:

**Baseline characteristics of intervention versus control group**

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<tr>
<th></th>
<th>Intervention (n=49)</th>
<th>Control (n=54)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Male/Female</strong></td>
<td>25/24</td>
<td>32/22</td>
</tr>
<tr>
<td><strong>Smokers</strong></td>
<td>16</td>
<td>23</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>67 (4)</td>
<td>68 (5)</td>
</tr>
<tr>
<td><strong>FEV&lt;sub&gt;1&lt;/sub&gt;, % predicted</strong></td>
<td>49 (8)</td>
<td>49 (8)</td>
</tr>
<tr>
<td><strong>BMI</strong></td>
<td>28 (6)</td>
<td>27 (6)</td>
</tr>
<tr>
<td><strong>6MWT (metres)</strong></td>
<td>391 (89)</td>
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<tr>
<td><strong>CCQ, 0-6</strong></td>
<td>2 (1)</td>
<td>2 (1)</td>
</tr>
<tr>
<td><strong>Exacerbations (n)</strong></td>
<td>0.8 (1.2)</td>
<td>0.4 (1.1)</td>
</tr>
</tbody>
</table>

---

**Figure 1.** Number of included and excluded patients and the reasons for loss to follow-up
Data collection

Assessments
Assessments in the intervention group were performed at baseline before the programme started and after two months, five months and one year. Exacerbations, smoking and drugs were assessed through the patient records from one year before the intervention until one year after. All assessments were conducted at each PHC centre by the COPD nurse. The control group was assessed at baseline and after one year by a nurse specialising in public health care who not was involved in the study but has had education in the assessments. The patient records were assessed by the author.

The functional capacity was assessed with a six-minute walking test (6MWT)\(^{126}\). The patient is asked to walk along a measured line, and the distance covered is measured after six minutes\(^{126}\). In a review of available methods and their feasibility in PHC, the 6MWT was found to be the most reliable functional capacity test\(^{127}\).

HRQoL was assessed using CCQ\(^{54}\). CCQ is a disease-specific questionnaire consisting of 10 questions in a seven-point scale between 0 as “asymptomatic/no limitations” and 6 as “extremely symptomatic/totally limited”\(^{54}\). CCQ examines HRQoL in three dimensions: symptoms, functional state and mental state. The instrument of CCQ has been validity and reliability tested for Swedish conditions with a Cronbach’s alpha score of 0.84\(^{128}\).

Pulmonary function, FEV1/FVC and FEV1, % of predicted, was measured using routine spirometry\(^{129}\).

Body mass index (BMI) was calculated as weight (kg)/height\(^2\) (m)\(^{130}\).

The number of exacerbations, smoking status and drugs prescribed related to COPD – i.e. inhaled corticosteroids, short- and long-acting \(\beta_2\), combination therapy, tiotropium bromide and ipratropium – were assessed.

Patients’ experience of the nurse-led multidisciplinary programme (III)

Participants, sampling and setting
Twenty patients participated in Study III (Table 6). A total of 49 PHC patients with COPD, GOLD stages 2 to 3, had participated in the six-week nurse-led multidisciplinary programme one year previously (II). All 25 who resided in one of the county council areas were invited to attend the interviews. This convenience sampling was based on the assumption that the
sample size would be large enough to capture a variety of experiences within the group. Four patients declined participation, and in one case the address was unknown. Therefore, 20 patients who had completed the programme participated in the interview study.

### Table 6. Demographic data of participants (n=20)

<table>
<thead>
<tr>
<th>Background variable</th>
<th>Number</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>68</td>
<td>62-78</td>
<td></td>
</tr>
<tr>
<td>FEV₁ (% of pred.)</td>
<td>44.5</td>
<td>27-67</td>
<td></td>
</tr>
<tr>
<td>Male/Female</td>
<td>13/7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smokers</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status (single/partner)</td>
<td>5/15</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Data collection

Qualitative interviews were conducted by the author in May and June 2009 at a location chosen by the patient, which was either in their homes or at their PHC centre. The interviews were semi-structured and focused on the patients' experiences of the PHC nurse-led multidisciplinary programme; they lasted 15 to 40 minutes. An interview guide was used containing six main questions about experiences of rehabilitation, inspired by Öhman et al. (Table 7).

### Table 7. Description of the interview guide

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Example of follow-up questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you remember of the multidisciplinary programme?</td>
<td>What do you mean?</td>
</tr>
<tr>
<td>What has been useful of what you learned in the programme? Was there anything missing?</td>
<td>Can you tell me more?</td>
</tr>
<tr>
<td>Is there anything in the programme you haven’t used? Why?</td>
<td>How did you handle the situation?</td>
</tr>
<tr>
<td>What experience do you have of your everyday life that has changed after the programme?</td>
<td>How did you feel then?</td>
</tr>
<tr>
<td>How is your situation in your experience of breathlessness and tiredness (the two most troublesome symptoms), put in relation to your everyday situation? Is there a difference after the programme?</td>
<td></td>
</tr>
<tr>
<td>Can you tell me about your relation to family members and friends? Is there a difference after the rehabilitation?</td>
<td></td>
</tr>
</tbody>
</table>
Individual follow-up questions were asked depending on what arose during the interviews, which were audio-taped and transcribed verbatim. A pilot interview to test the usefulness of the questions led to no changes and was therefore included in the study.

**Next of kin’s experience of life together with a patient suffering from COPD two years after the latter’s attending a nurse-led multidisciplinary programme (IV)**

**Participants, sampling and setting**

The number of participants in Study IV was 20 next of kin to patients with COPD (Table 8).

**Table 8. Demographics for next of kin to patients with COPD (n=20).**

<table>
<thead>
<tr>
<th>Background variable</th>
<th>Number of participants (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouses/child/live-apart, (n)</td>
<td>18/1/1</td>
</tr>
<tr>
<td>Male/female, (n)</td>
<td>6/14</td>
</tr>
<tr>
<td>Age, median (range)</td>
<td>66 (38 – 78)</td>
</tr>
<tr>
<td>Smokers, (n)</td>
<td>5</td>
</tr>
<tr>
<td>Participated in the session for next of kin (n)</td>
<td>15</td>
</tr>
</tbody>
</table>

All of the remained 44 PHC patients with COPD, GOLD stages 2 and 3, who had participated in and completed the six-week nurse-led multidisciplinary programme with follow-ups during one year (II) were asked to nominate and give permission to contact one of their next of kin about participation in the interview study. A flow chart of the process of recruitment is presented in Figure 2. The participants resided in two county councils in the middle of Sweden. Fifteen had participated at the session for next of kin in the programme when they were invited.
Individual follow-up questions were asked depending on what arose during the interviews, which were audio-taped and transcribed verbatim. A pilot interview to test the usefulness of the questions led to no changes and was therefore included in the study.

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Data collection
The author performed qualitative interviews in the year 2010 at a location chosen by the next of kin, which was either their PHC centre or their homes. The interviews were semi-structured and focused on next of kin experiences of their life together with a patient with COPD who had completed the PHC nurse-led multidisciplinary programme. The interviews lasted 16 to 46 minutes. An interview guide was used containing nine main questions about experiences of rehabilitation (Table 9). Individual follow-up questions were asked depending on what arose during the interviews. The interviews were audio-taped and transcribed verbatim. A pilot interview to test the usefulness of the questions led to no changes and was included in the study.

Figure 2. Participant flow chart
Table 9. Description of the interview guide

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Example of follow-up questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your partner participated in a nurse-led multidisciplinary programme – did</td>
<td>What do you mean?</td>
</tr>
<tr>
<td>you talk about what was happening?</td>
<td></td>
</tr>
<tr>
<td>Is your experience that there were any changes in everyday life at home after</td>
<td>What do you mean?</td>
</tr>
<tr>
<td>the programme?</td>
<td></td>
</tr>
<tr>
<td>What experience do you have of your everyday life? Has it changed after the</td>
<td>Can you tell me more?</td>
</tr>
<tr>
<td>programme? Tell me about your situation at home, at work or in other parts</td>
<td></td>
</tr>
<tr>
<td>of your life after the programme!</td>
<td></td>
</tr>
<tr>
<td>To relative that participated in the information session: What experience do</td>
<td>How did you handle the situation?</td>
</tr>
<tr>
<td>you have of the information you got when you participated at one session?</td>
<td></td>
</tr>
<tr>
<td>Do you have any experience that he/she/you used anything that he/she/you</td>
<td>How did you feel then?</td>
</tr>
<tr>
<td>learned? Did your partner follow the individual home training programme?</td>
<td></td>
</tr>
<tr>
<td>What experience do you have of your own/partner’s breathlessness and</td>
<td></td>
</tr>
<tr>
<td>tiredness? Any difference after the programme?</td>
<td></td>
</tr>
<tr>
<td>Does the disease influence your relations with family and friends? Difference</td>
<td></td>
</tr>
<tr>
<td>after the programme? What does it mean for you?</td>
<td></td>
</tr>
<tr>
<td>To relative that did not participate in the information session: Why did you</td>
<td></td>
</tr>
<tr>
<td>participate? What could have led you participate?</td>
<td></td>
</tr>
<tr>
<td>To relative that participated in the information session: Why did you</td>
<td></td>
</tr>
<tr>
<td>participate? What led you participate?</td>
<td></td>
</tr>
</tbody>
</table>

Data analysis

Qualitative analysis (I, III and IV):

The interview texts were analysed using qualitative content analysis methodology, as described by Graneheim and Lundman\cite{132}. Content analysis was chosen (I, III, IV) when the purpose was to have the participants describe themselves and their social life\cite{120}, that is, an inquiry into a human being and his or her social world\cite{119}. In content analysis the purpose is to identify the patterns and variations in communication\cite{120}. The method is established in the ontology from both positivistic and humanistic thinking\cite{119-120}. Epistemological content analysis originates in sociology, philosophy and behavioural sciences\cite{119}.
The analysis includes both manifest analysis (close to the text) and latent analysis (the underlying meaning). A first step involved reading the text carefully several times and dividing it into meaning units corresponding to the aim of the study (I, III, IV). Up to this stage the analysis was performed in the same way in the three studies, but in the next steps there are some differences in the analysis. The purpose of this step (I) was to condense the meaning units to shorten the sentences but still retain the core of the message. The condensed meaning unit was abstracted and labelled as a code, illustrated in Table 10.

Table 10. Example of the analysis process first step, from meaning units to codes (I)

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Those who are newly diagnosed are often sad.</td>
<td>Newly diagnosed are often sad.</td>
<td>See sadness at new diagnosis</td>
</tr>
<tr>
<td>After they have had the diagnosis for a while, they discover that life has not ended.</td>
<td>Life has not ended in spite of diagnosis, discovers after a while.</td>
<td>See hope grow</td>
</tr>
<tr>
<td>I try to help them through pushing back of their guilt feelings and encourage other things instead.</td>
<td>Push back feelings of guilt and encourage other things.</td>
<td>Support for self-care through encouragement</td>
</tr>
</tbody>
</table>

In studies III and IV a software program, QSR NVivo\textsuperscript{80} \textsuperscript{133} was used as a tool in the analysis process. Meaning units were identified based on the aim and were labelled as codes, a process whereby the code became something between a condensed meaning unit and a code. The various codes were then put together in groups based on similarities and differences (I, III–IV). The groups of codes were sorted and abstracted, and clustered into sub-categories (I, IV) and categories (I, III–IV), that constituted the manifest analysis (close to the text). The categories can be identified as a thread throughout the codes. The categories were then grouped based on common content and abstracted into sub-themes (III, IV). Categories (I) and sub-themes (III, IV) were then reflected on, discussed and refined to identify and formulate unifying themes (I, III, IV), a process whereby parts are formed into a whole. The theme and sub-themes are interpretations of the underlying meaning and the result of latent analysis of the interview text\textsuperscript{132}. 

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\textsuperscript{80} QSR NVivo is a software tool for managing and analysing qualitative data, designed to help researchers in the social sciences, health sciences, humanities, and business. It offers a range of features for coding, data management, and analysis. 

\textsuperscript{132} Latent analysis refers to the deeper, underlying meaning in the data, as opposed to manifest analysis, which is more literal and directly observed. 

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\textsuperscript{133} NVivo is a trademark of QSR International.
Quantitative analysis (II)
For analysis of the parametric variables age, FEV₁, BMI, 6MWT and exacerbation frequency, comparisons between and within the groups were performed using independent t-tests and paired sample t-tests. The mean differences of change from baseline to the one-year follow-up in 6MWT and exacerbation frequency between the groups were tested using t-tests for independent groups. For ordinal scale variables such as CCQ, comparisons between and within the groups were calculated using the Mann-Whitney U test and Wilcoxon signed-rank test. Statistical analysis was performed using SPSS 16.0.
ETHICAL CONSIDERATIONS

Studies involving interviews with staff were not subject to Swedish legislation on ethical approval at the time when Study I was performed\textsuperscript{134}. Ethical regulations were followed nonetheless. In studies II, III and IV the Research Ethic Committee in Uppsala, Sweden, approved the studies, (II: No. 2006/322, III: No. 2009/058, IV: No. 2009/058/1). The patients in both groups in Study II and all participants in studies I, III and IV were invited to participate through an information letter that included informed consent. In all four studies participation was voluntary, and participants were allowed to discontinue at any time without the risk that their ordinary work (I) or care (II, III, IV) would be influenced. All studies were conducted according to the Declaration of Helsinki on medical ethics\textsuperscript{135}.

In interviews (I, III, IV) strong emotions, even unpleasant emotions, can be expected to arise. Participants were informed that if they felt in need of talking, they could contact the interviewer, who was in charge of mediating contacts for psychological help if it was needed. No one has asked for that kind of help so far. In the intervention study (II) patients were offered individual contacts with the different health professionals in the team at their PHC centre.

There are aspects specific to being in the control group as patients in Study II given that they had no intervention. All patients in the control group were informed both verbally and in writing that participation was voluntary. Their care would not be affected, and they would have their usual care from their COPD clinic in their PHC centre whether they chose to participate or not. The patients in the control group were offered participation in a programme after the intervention study if positive outcomes were shown.

Recruitment of participants through patients, as in Study IV, is also worth discussing. Asking the patient for permission to contact a next of kin whom he or she has nominated was judged to be optimal for both the patient and the next of kin.

All data from the studies were managed with confidentiality that no unauthorised individuals had access to information about participants. All data were coded, and information was confidential in the databases that were set up. The data have been confidentially handled and presented on a group basis. Citations were coded and cited verbatim.
RESULTS

COPD nurses’ experience of patient education (I)
The results in Study I showed that the COPD nurses fluctuated between security and insecurity in their patient education. This was demonstrated by the main themes of the study. The first theme that emerged was Receiving support results in a feeling of security, which enables the development of patient education. The nurses had support from their colleagues and found it stimulating. They met the patients’ worries and fears, and they created contact with the patients. After the patient education the nurses could see patients who felt calmer and more secure. The nurses tried to relieve the patients’ sense of guilt by inspiring hope and adapted the care individually. They supported the patient in self-care by conveying knowledge. The nurses had a feeling of being important for the patient.

The second theme that emerged was Lack of support results in a feeling of insecurity, which makes it difficult to develop patient education. The nurses lacked support, structure and time. They had to handle negative attitudes from other clinic staff. A feeling of insufficiency and powerlessness was felt in the task of patient education (Table 11).

All nurses wanted requirements for more structured patient education, time and collaboration with their co-workers in their PHC centre.

Table 11. Asthma/COPD nurses’ experience of educating patients with COPD in PHC

<table>
<thead>
<tr>
<th>Theme</th>
<th>Receiving support resulted in a feeling of security, which enabled the development of patient education</th>
<th>A lack of support resulted in a feeling of insecurity, which made it difficult to develop patient education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Categories</td>
<td>Categories</td>
</tr>
<tr>
<td></td>
<td>Support from colleagues was stimulating</td>
<td>Lack of support, structure and time</td>
</tr>
<tr>
<td></td>
<td>Meeting the patients’ worries and fears</td>
<td>Handling negative attitudes from other clinic staff</td>
</tr>
<tr>
<td></td>
<td>Trying to relieve the patients’ sense of guilt</td>
<td>A feeling of inadequacy in the task of patient education</td>
</tr>
<tr>
<td></td>
<td>Supporting the patient in self-care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The feeling of being important for the patient</td>
<td></td>
</tr>
</tbody>
</table>
Effects of a nurse-led multidisciplinary programme of pulmonary rehabilitation (II)

The six-week nurse-led multidisciplinary programme in Study II showed no significant differences between the intervention group and the control group at baseline with regard to smoking, age, FEV₁, BMI, 6MWT, CCQ and exacerbation frequency.

No significant differences between the groups were shown in 6MWT and CCQ at the one-year follow-up. The exacerbation frequency decreased by 0.24 within the intervention group and increased by 0.26 exacerbations within the control group. The mean difference of change between the groups in exacerbation frequency was statistically significant (p=0.009) during the year after baseline (Table 12).

Within both the intervention and the control groups the patients improved their 6MWT significantly after one year, by 22 m and 38 m, respectively. Within the intervention group the patients increased their CCQ significantly after one year (p=0.022).

The patients with COPD in PHC were predominant overweight or obese. Four patients of 16 in the intervention group and seven of 23 in the control group stopped smoking during the study.

Table 12. Investigation of the effects of a nurse-led multidisciplinary programme in PHC on functional capacity, HRQoL and exacerbations among patients with COPD

<table>
<thead>
<tr>
<th></th>
<th>Intervention (n=44)</th>
<th>Control (n=45)</th>
<th>Mean diff. of change</th>
</tr>
</thead>
<tbody>
<tr>
<td>6MWT, m*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>388 (94)</td>
<td>360 (88)</td>
<td></td>
</tr>
<tr>
<td>1 year</td>
<td>22 (44)</td>
<td>38 (76)</td>
<td>−45 – 11</td>
</tr>
<tr>
<td>Mean diff (SD)</td>
<td></td>
<td></td>
<td>0.239</td>
</tr>
<tr>
<td>Exacerbations (n)</td>
<td>0.8 (1.2)</td>
<td>0.4 (1.1)</td>
<td>0.4 (0.9)</td>
</tr>
<tr>
<td>−0.2 (0.9)</td>
<td>−0.2 (0.9)</td>
<td>−0.9 − 0.1</td>
<td>0.009</td>
</tr>
<tr>
<td>CCQ, 0-6</td>
<td>2.0 (1.0)</td>
<td>2.0 (1.0)</td>
<td>0.8 (0.8)</td>
</tr>
<tr>
<td>1.7 (0.9)</td>
<td>1.7 (0.8)</td>
<td>0.866</td>
<td></td>
</tr>
</tbody>
</table>

*Intervention group (n=38), control group (n=42)

Patients’ experience of the nurse-led multidisciplinary programme (III)

In Study III, performed one year after completing the programme, the experiences of the patients were shown in the theme *I am allowing myself to live life at my own pace*, and three sub-themes: *Helping me to regain control over my life*, *Obtaining insights into the limitations of my life*, and *Being of no crucial relevance to me* (Table 13). The programme had given some patients tools to manage daily life. The patients reported that the
nurse-led multidisciplinary programme had given them an opportunity to gain control of the disease and their life. They were careful to look after themselves and wanted to live a life as well as possible.

The patients felt frustrated about and irritated by their physical weakness, and some patients had gained insights into their own limitations. Yet others expressed that the multidisciplinary programme was of no crucial relevance to them. These patients experienced that it did not change their everyday life. Many did not even remember the programme. Some expressed resignation and lived life as best they could. They had adapted to the disease and lived at their own pace, regardless of the programme.

Almost all expressed fear of some kind; the knowledge provided by the programme created fear while, for others, the fear decreased but did not vanish after the programme. Taking everything into account, all participants now allowed themselves to live life at their own pace, but for various reasons, and furthermore, life was somehow shadowed by fear of an uncertain future.

Table 13. Descriptions of the experiences of patients with COPD of participating in a nurse-led multidisciplinary programme in primary health care setting one year after completing the programme

<table>
<thead>
<tr>
<th>Theme</th>
<th>I am allowing me to live life at my own pace</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-theme</td>
<td>Helping me to regain control over my life</td>
</tr>
<tr>
<td></td>
<td>Obtaining insights into the limitations of my life</td>
</tr>
<tr>
<td></td>
<td>Being of no crucial relevance to me</td>
</tr>
</tbody>
</table>

Next of kin's experience of life together with a patient suffering from COPD two years after the latter's attending a nurse-led multidisciplinary programme (IV)

The findings in Study IV are presented in one theme, *Life remains overshadowed by illness*, and two sub-themes; *Life has its positive sides* and *Living with a sense of vulnerability* (Table 14). The theme that emerged from next of kin interviews two years after the programme illuminates that illness remained overshadowed their lives together in spite of the nurse-led multidisciplinary programme. To summarize they described a daily life that has its positive sides with increased togetherness but also that they live a burdensome life and feel vulnerable. The fluctuations between feelings of togetherness and a heavy burden varied, depending on different situations. When the patient was not doing well, the next of kin were worried and
took a lot of responsibility, but when there were good days, everything was well. Yet, life together was overshadowed by illness.

In the sub-theme that describes that life had its positive sides was the ability to communicate a major factor in acceptance and understanding of the situation and gave the relation a good base. Some had been given the opportunity through the programme to start communicating and sharing their troubles and could plan for a future together. The relation had improved because of the programme. That both were able to have and use knowledge facilitated life together. Both the next of kin and the patient felt calmer after the programme; the breathlessness did not frighten them so much anymore. The patient kept on with training and the breathing technique that was learnt in the programme and was now able to exert him- or herself, which meant that the couple could be more active together. They saw the importance of having time for themselves to develop strategies to handle their own life as well. By the programme next of kin felt relieved in that they now were more comfortable with the PHC centre. They did not feel so lonely with the responsibility anymore.

The second sub-theme describes that next of kin were living with a sense of vulnerability. Next of kin was seen as really caring for the patient and that they were worried and watchful. They had a feeling that everything hung on their shoulders, a feeling that everything depended on them, both because they were emotionally engaged and because they took on the responsibility. They have espoused a role, to take care of everyone and everything, not only the patient. That was a heavy burden for the next of kin, and it required a great effort to take a lot of consideration and responsibility. They did not see COPD as the worst disease; it was the co-morbidity that created the problems. The next of kin’s life was limited, they had feelings of guilt and shortcomings, and they felt there was no space for them. Their social lives were affected by the situation, and it was difficult to meet the reactions of those around.

Table 14. Description of next of kin’s experience of life together with a patient suffering from COPD, two years after the latter’s participation in a nurse-led multidisciplinary programme of pulmonary rehabilitation in primary health care

<table>
<thead>
<tr>
<th>Theme</th>
<th>Life remains overshadowed by illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-theme</td>
<td>Life has its positive sides</td>
</tr>
<tr>
<td></td>
<td>Living with a sense of vulnerability</td>
</tr>
</tbody>
</table>
DISCUSSION

The COPD nurses

The COPD nurses in Study I fluctuated between security and insecurity in their patient education for patients with COPD because of a lack of support (I). Perhaps the issue is more than just whether the nurses received support; it could also be related to the personality, creativity and experience of the nurse. In another study, which was video-taped, the consultations at nurse-led clinics concerned mainly physical medical investigations such as spirometry, and the communication contained less focus on the patients’ cognitive and emotional statuses. Most of the self-management education was performed through information without shared understanding. Marton, a scholar within research in learning, reported a weak correlation between “goals for teaching” (what teachers say they want to do) and “actions for teaching” (what they actually do). There is a lack of relation between intention and performing, which might be seen when comparing Study I to the video-taped one. It could have been so that the nurses say one thing as in the interviews in Study I and perform something else as was shown in the video-taped study. That could be a limitation in Study I that the interviews would have been combined with video-taping. However, they are probably not aware of it and need help to reflect on their patient education so as to be more secure and get more relation between intention and performing.

The nurses expressed insecurity in their education role (I). Nurse-led asthma/COPD clinics were established in PHC centres at the beginning of 1990s, and in the year 2005 about 50% of the PHC centres in Sweden had a nurse-led asthma/COPD clinic, which means that it is a new occurrence. There are probably several established today, in the year 2011, because the organisation of PHC has changed recently, and several regions have asthma/COPD clinics as a criterion of quality for the establishment of a PHC centre. Still, there is no clear definition of a job description, what the nurses’ tasks are in the clinic, which might be a reason for the nurses’ insecurity. There exist criteria on what such an approved clinic would contain, but not on how patient education and other skills should be performed. According to Marton is knowledge the understanding of content. To make people learn is to direct it in their interests and relate the content towards that. The nurse must be able to coach the patient by simply encouraging, supporting and providing timely feedback, allowing the patient to grow and excel, to build on his or her strengths and resources, and to develop accountability in decision making directed towards goal attain-
ment, with the focus on who the patient is\textsuperscript{111}. In education related to lifestyle changes, one short-term education programme for patients as in Study II is not sufficient; reinforcement and follow-up are also required\textsuperscript{68}. One advantage of the PHC relationship is that patients ought to be supported over time\textsuperscript{136}, and coaching can in future interventions be carried on in the clinical reality. Patient education must be paid more attention in PHC.

All nurses in Study I expressed that they wanted more education, support, time, collaboration and structure in their COPD clinic. The COPD nurses who worked clinically in the setting of Study II received more education, support and time because of their participation in the study. They also were involved in collaborations because the participating PHC centre had to set up teams, and they received structure because of the six-week programme and guidelines on education that were included. However, they lacked education about the group process and how to lead them, which is a limitation in the design of Study II.

The COPD nurses’ patient education was modified as they now (II) had to educate in a group setting; previously they had only educated the patients individually. The main task for COPD nurses is to promote lifestyle changes\textsuperscript{94,112}, but they are in need of more knowledge on how to educate, both in group and individually, as the nurses experienced in Study I. According to the work by Marton\textsuperscript{102} the COPD nurses must have the opportunity to learn “how”, not only “what”, to be able to coach on behavioural changes, which might not be available to a great extent in their further work as nurses in public health.

The programme
In guidelines for PR the main component is physical exercise but also patient education in different fields\textsuperscript{2,28} which is included in the nurse-led multidisciplinary programme (II). One limitation was that some topics in the programme in Study II were not given attention, such as fatigue, osteoporosis and urinary incontinency. Sexual activity was raised first in Study IV by a next of kin. During the design of the study urinary incontinency and sexual activity came under discussion, but it was decided to not give them much attention unless the patients or next of kin mentioned the subject themselves. These topics were considered difficult to discuss in group sessions; the group had to be very safe together, which is difficult to form an opinion about in a programme of only six weeks’ duration. Fatigue was discussed in the group sessions; it came up during discussion of other subjects as a common problem in COPD. It was not assessed in Study II, however, because the programme became compressed into six weeks, and what was assessed was dealt with the clinical reality. This situation was a limita-
tion of the study but also a strength in that Study II was performed in the clinical reality.

In Study II an attempt was to standardise patient education through the use of prepared content guidelines as, according to Piredda patient education is a planned process of activities. Different nurses were group leaders, and, together with other team members, they held the patient education, which could be a limitation of the study, but that is not possible to standardise. Team members are also individuals, and their contributions could be related to the personalities, creativity and experience of the professionals. However, working in teams combining various disciplines in an integrated model improves care processes and patient outcomes in COPD which was a strength in Study II.

One limitation in Study II was that the COPD nurses and their team were provided with no information about group education. In Study III participants experienced that the group education had not been fully worked out when some participants raised obstacles with the group in the intervention (II), and in Study IV it emerged that some next of kin had misunderstood the given information. In group education attention must be paid not only to the content but also to the aim of the education and the process of delivery. It is important to identify participants’ prior knowledge and allow the whole group to discuss what others have said. The COPD nurse can be there to lead the discussion and add information if needed and let the participants work out the correct answer between themselves but ensure that misconceptions do not arise. It might be uncomfortable for the COPD nurse to step outside the traditional role of information giving, but approaching the issue from the participants’ perspective enhances learning and keeps people engaged.

To change behaviour in lifestyle, longer PR programmes together with individual support might be needed, and the next of kin could be involved to a higher degree. That is a limitation in Study II.

The effects

In the nurse-led multidisciplinary PR programme in Study II the effects were evaluated, and no differences were found between the two groups in functional capacity and HRQoL. In exacerbations there was a statistically significant change in the mean difference between the groups. Exacerbations decreased in the intervention group and increased in the control group. Functional capacity increased in both groups. Patients in both groups were being cared for in their PHC centre prior to Study II. They already had learned what they had to do, i.e. start regular physical activity. The same phenomenon was seen even related to smoking habits. According
to Marton, successful learning is possible only when the individual have faith to his/her competence to learn and feel that learning will be personal profitable and important\textsuperscript{102} which might have been the reason in this case. All patients with COPD in PHC are offered smoking cessation support at the time of diagnosis. Now they were reminded, and more succeeded in stopping smoking in both the intervention group (25\%) and the control group (30\%) in Study II. That can be seen as a good result, given that another study has shown that smoking cessation advice together with pharmacological treatment has the best results, about 30\%\textsuperscript{138}. Some of the next of kin in Study IV also stopped smoking or at least started the process of action towards stopping smoking through the programme in Study II, so the programme was motivational even for next of kin. The concept motivation has been used to describe the power that creates the moving in learning\textsuperscript{102}.

Another finding that was somewhat surprising in Study II was that the participating patients with COPD in PHC were predominantly overweight or obese. Patients in hospital settings are predominantly underweight\textsuperscript{1}. It is a challenge for PHC to meet patients’ need for dietary advice to reduce weight. In the patient education in Study II the advice focused mainly on underweight patients, which is the focus in existing guidelines\textsuperscript{2, 28, 70, 123}. There is a need for dieticians in the programme because advice for overweight patients with COPD requires more specific interventions, such as nutritional education, restricted calorie and meal planning, encouragement for weight loss and psychological support\textsuperscript{28}.

Study II showed positive outcomes in spite of the lower level of the programme, six weeks with one two-hour session each week, including physical activity. A typical course of PR consists of one- to three-hour sessions, two to three times per week for six to 12 weeks with physical activity involved\textsuperscript{2, 28}. To transfer the results of the current programme in Study II to a clinically important level, minimal clinically important difference (MCID) can be used, which means that it can serve as a basis for what constitutes a meaningful effect of an intervention for the patient\textsuperscript{139}. However, MCID can be judged only at the group level, not in terms of the individual patient’s improvement. Only the individual patient can inform the clinician about his/her perceived improvement\textsuperscript{139}. The MCID in 6MWT, which assesses functional capacity, is $26 \text{ m} \pm 2 \text{ m}$ in COPD in GOLD stadium III\textsuperscript{140}, which characterised the patients in Study II. The patients in both the intervention group and the control group increased their 6MWT after one year, by 22 m and 38 m, respectively, which means that they improved their functional capacity. Surprisingly, the intervention group did not reach MCID, but the control group did. That supports the notion that these
nurse-led clinics in PHC are important to the patients. The MCID for the CCQ, which assesses HRQoL, has shown an average score of 0.4 for the total score\textsuperscript{128, 141}. In Study II the MCID was reached after two months in the intervention group but did not persist during the year. In the control group no MCID was reached in HRQoL. The MCID in the number of exacerbations represents a change of one less exacerbation per year\textsuperscript{142}. The patients in the intervention group decreased their number of exacerbations, and the control group increased their number; the differences were statistically significant. This shows that the intervention had an effect on the MCID of exacerbations, and it might have improved the patients’ health status. However, investigations are required on how these outcomes can be translated into long-term effects.

**The patients’ perspective**

Within the intervention group in Study II the patients’ HRQoL improved during the year. The patients described in Study III that they were satisfied and calm, and that the breathlessness did not frighten as much as it had previously (III). This might explain the decreased frequency of exacerbations in Study II. The nurses in Study I experienced difficulty in providing education prior to the intervention, but the patients in Study III described that they had learned new information, so the team must have been successful, in line with another study\textsuperscript{117}. The nurses in Study I that educated alone was insecure but within a team they might became more secure and felt support. To have support was important, in another study, when it was found that the task-oriented nurses needed more support from management and colleagues so as to be individual-oriented\textsuperscript{95}. When the PHC centres had to build teams in Study II it was an opportunity for successful patient education.

The patients reported in Study III that they had learned to allow themselves to live at their own pace, some on their own and some through the programme. These findings were in line with previous studies in hospital settings\textsuperscript{80-84}. The programme in Study II was described in Study III as having given the patients an opportunity to gain control of the disease and their life, and patients’ reports were similar to results in Study II as a fairly good HRQoL. Meaning and understanding for the patient is a central matter\textsuperscript{102}. In spite of that, almost all expressed fear of some kind; the knowledge provided by the programme created fear for some while, for others, the fear decreased but did not vanish after the programme. Fear has been reported related to specific topics such as exercise\textsuperscript{143-144}, falling\textsuperscript{145}, inhaling corticosteroids\textsuperscript{146}, sleeping\textsuperscript{21}, death and dying\textsuperscript{147} and, most commonly, breathlessness\textsuperscript{35, 144}. Patients’ fear must be given more attention in the fu-
ture, especially since some patients in Study III reported more fear after they had gained knowledge. Fear might be openly discussed in the group and the patients require gaining confidence that they can act to take some control over potential threats or stressors, according to Banduras theory about self-efficacy. The social worker in the programme educated patients about anxiety and depression, but fear was not touched on, which must be taken into account in further interventions.

Both patients with COPD and next of kin reported problems with co-morbidity (III, IV). There is a recognised connection between patients with COPD and heart disease, for example. In one study these patients, compared to patients without associated heart diseases, required more respiratory drugs, had a worse HRQoL, consumed more resources and incurred more expenses. That correlation is in need of more attention in PHC for the purpose of improving HRQoL as well as survival of patients with COPD. Although co-morbidity was not investigated in Study II, nurses specialising in public health care and PHC seem to be suitable to care for patients with COPD and next of kin because of their function as generalists and the complex nature of COPD with co-morbidity. It is an advantage to have knowledge in several fields when caring for patients with COPD.

**Next of kin’s perspective**

Next of kin’s life together with the patient with COPD remained overshadowed by the illness in spite of the programme. The next of kin carried a heavy burden, involving a great effort to take on much consideration and responsibility, but they felt relieved in that they now were more comfortable with the PHC centre after Study II. They felt less lonely with the responsibility, especially when they did not see COPD as the worst disease, when it was the co-morbidity that created problems.

Study IV revealed positive outcomes of the programme. For example, the next of kin experienced that life had its positive sides. They were able to start to communicate, and togetherness was improved; couples could be more active together. These findings showed improvements through the programme in Study II compared to previous studies about experiences of life together with a patient with COPD. These studies reported no communication ability and less togetherness. Next of kin in Study IV expressed that they had gained new knowledge through the programme in Study II and could better understand the patients, which made life easier. This is important given that a review has stated that next of kin have a major impact in helping patients to overcome, or at least manage, anxiety and might also reduce hospitalisation through their contribution to care. Even so, however, next of kin also feared an uncertain future present. Next of
kin should be paid more attention in PHC because of their contribution of care and to avoid health problems among them.

Over studies, III and IV, there were shadows of fear and uncertainty. In conclusion, COPD is a frightening and severe disease, both to have and to manage by patients and next of kin, but with a six-week nurse-led multidisciplinary programme of PR the fears and uncertainty can be attenuated.

**Method discussion**

The aim of this doctoral thesis is threefold; to modify, to evaluate and to describe the effects and experiences of a nurse-led multidisciplinary programme for pulmonary rehabilitation. The term of evaluation is used partly as “first-generation evaluation,” which stipulates effects through measurements, and partly as “second-generation evaluation”, so-called “formative evaluation”\(^{120}\). This can describe patterns of strengths and weaknesses as the improvements that have appeared can be recommended\(^{149}\). The studies took place within a specific context, and attention is directed to the local situation without the possibility of controlling the circumstances\(^{149}\).

**Trustworthiness**

In order to strengthen the study trustworthiness through the presentation of the research processes as carefully as possible in all papers (I–IV). Another attempt to strengthen trustworthiness in the studies (I–IV) is that both positive and negative results of the programme are presented.

In order to strengthen credibility in the qualitative studies (I, III, IV), the co-authors participated in the various steps of the analysis process. So that the analysis could be considered from different perspectives, the results were discussed at research seminars. Dependability was enhanced by the use of an interview guide to ensure that all interviews were conducted around the same topics. The use of NVivo\(^8\)\(^\circ\) in the data analysis (III, IV) is also seen as a tool to strengthening the dependability, as it was easy to move back and forth in the interview text during the coding and categorising. Some concerns about using software for data analysis have been raised in the literature, such as the risk that codes could lose their contextual meanings\(^{119-120}\), a critique with which the author disagrees. Quotations from the interviews are presented in the results in order to strengthen the credibility and dependability.

One weakness in study design in Study III could be that only patients from one county council were invited to participate. However, it was estimated that the sample size was sufficient to meet the variations in the patients’ experiences. The most appropriate course of action would have been
if all patients in Study II had been invited, but at the time the study was performed, sufficient resources and time were unavailable.

Another weakness of the design in Study IV might be that it is unknown whether the positive outcomes in next of kin two years after the intervention identified during the course of the study were a result of the passage of time rather than a result of the nurse-led multidisciplinary programme.

While the findings cannot be generalised, they can be transferred to provide increased understanding of similar situations in a new context, based on the information provided by the participants and the study setting.

External and internal validity
External validity concerns generalisability, and internal validity relates to the study design. Threats to internal validity include history, selection, testing, instrumentation, maturation and mortality\(^\text{121}\).

One threat to external validity could be the expectancy effect. In Study II the control group members also increased their functional capacity and there were no statistically significant differences between the groups. As well, an equal number of participants stopped smoking in the both groups. Perhaps the expectancy effects caused participants to behave in a particular manner because they were aware of participating in a study, i.e. the Hawthorne effect\(^\text{121}\). Study II has weak external validity because of the low power, 25%, which means that findings should be interpreted with caution and are not in fully generalisable.

The internal validity could be threatened by history because no differences were evident between the groups after one year. As well, the patients in the control group already knew what they had to do; they had received information previously in their PHC centre on starting regular physical activity or stopping smoking, and now they were reminded. However, there were statistically significant differences between the groups’ exacerbation frequencies. The intervention group decreased their number of exacerbations, and the control group increased theirs. The conclusion of that is that the nurse-led multidisciplinary programme influenced the intervention group.

Another threat to the internal validity could be a selection bias. The PHC centres in Study II were aimed to be randomised, but it was difficult to build a team at each PHC centre. This might have resulted in a situation whereby only engaged PHC centres accepted, which could be a selection bias. If that had been a problem, however, there would probably have been bigger differences between the groups. Second, the aim was also to randomise the patients, but too few patients with COPD who met the inclusion criteria were eligible. However, threats to validity related to selection
were mitigated in that the selected patients in the two groups were equal at baseline.

Selection bias might also have been present in that patients were selected based on a medical approach, such as spirometry. In some patients there were no changes in functional capacity or HRQoL after the programme and after one year. The patients function in everyday life varied in spite they had the same value in spirometry; some had a quite good function already from base-line when others had not. It would have been preferable for the selection to be made based on function in everyday life, such as the International Functional Classification (ICF) or BODE (body mass index, obstruction, dyspnoea, exercise) index in order to include them who were best in need of a programme.

One threat to internal validity could be the testing by CCQ. CCQ is a valid and reliable instrument in assessing HRQoL tested for Swedish condition with a Cronbach’s alpha score of 0.84. The total score is calculated by adding the scores of the 10 items, then dividing by 10. The instrument is validated to be counted in terms of mean value and standard deviation, which was also used in Study II, but Student’s t-test was not used as recommended. Instead, the Wilcoxon signed-rank test and Mann-Whitney U test was used, because ordinal scales are not, or are seldom, normally distributed. The numbers in an ordinal scale have no mathematical properties and would be calculated in terms of median value. In Study II it was decided not to use median values because CCQ was not validated in that way; only in mean values were.

It is known that if a researcher is personally involved in an intervention, questions can arise about neutrality in relation to the results. Evidence shows that the researcher’s positive expectations can influence the results, called allegiance bias. In this case (II), it can be discussed in relation to the fact that the COPD nurses made the assessments of the participating patients in the intervention group themselves. However, in the control group only one nurse specialising in public health care, who was not involved in the study, conducted the assessments.

There was no threat to internal validity related to mortality. No one died during the year in which Study II took place.
CONCLUSION

The conclusion in this doctoral thesis, from patients and next of kin’s perspective, are that patients with COPD and their next of kin live in the shadow of fear and uncertainty despite the nurse-led multidisciplinary programme of pulmonary rehabilitation. New knowledge has been derived that a programme could both raise fear and give calmness. The participants had gotten help in managing life with COPD as patients or next of kin through the programme, but this does not seem to be enough. Patients might need more education and follow-up on an individual basis during and after the programme. Next of kin need more attention to their own needs and more education about COPD related to how to be of help, although they by the programme felt a shared responsibility with the PHC. New knowledge that also was derived in this thesis is that next of kin did not see COPD as the worst disease. Their problems were with the comorbidity.

Six weeks of a nurse-led multidisciplinary programme of pulmonary rehabilitation was shown to influence the decreasing of exacerbations but no difference between the intervention group and the control group were found in functional capacity and HRQoL. COPD nurses described that they wanted more support in their education to patients with COPD when they sometimes experienced insecurity.

Implications for practice

Patients with COPD decrease their exacerbation frequency with the contribution of only a six-week nurse-led multidisciplinary programme of PR. This is an important finding because the patient will be spared suffering caused by deterioration related to the disease, and decreased HRQoL and functional capacity. The medical service and the patient will be spared emergency visits and hospital admissions. It is important that the programme continue in PHC. PR has great power to influence lifestyle changes and to improve patients’ everyday life. This thesis has illustrated that much can be done for the patient and next of kin even in PHC, beyond pharmacological treatment. However, all patients with COPD do not benefit from PR in groups; some would likely benefit more from individual education.

The fear and uncertainty in COPD must be taken into account when treating patients and their next of kin in PHC.

Patients with COPD in PHC in Study II were predominantly overweight or obese, which requires more professional care. This thesis confirms that a dietician should be employed in PHC, since that professional expertise is currently lacking, when further programmes of PR will be planned.
PHC centres are appropriate venues for managing COPD, especially when professionals in PHC are generalists, considering co-morbidities, but COPD nurses and PHC teams are in need of more education in learning and coaching. Also needed are helping the nurses to reflect on their own patient education practices in supervised groups.

**Future research**

The six-week nurse-led multidisciplinary programme of PR presented in this doctoral thesis is in need of future research and modification. A randomised controlled trial would be the most appropriate design to demonstrate generalisability of the results. Another sampling method should also be tried. Patients could be selected for interventions based on function in everyday life instead of severity of COPD as measured with spirometry.

The assessments that were made were suitable, but there might also be assessments of breathlessness, fatigue, self-efficacy and self-management when these factors concern the patient’s function in everyday life. Health economics is another subject that is important in future research.

All professionals in the team, especially the COPD nurse as a group leader, are in need of education in the pedagogy of learning and about group processes. The COPD nurses and the teams would be of interest in future research; for example, how they perform patient education after receiving their own education in learning and coaching.

Following future research, the programme would be modified so that a dietician would be involved and also combined with individual support to the patients together with regular follow-ups. In addition, the next of kin are in need of participation to a greater degree when they experience vulnerability and want to be of help. Sexuality and urinary incontinence would be paid greater attention in the programme when that is a source of trouble for the patient.

Fear and uncertainty related to COPD must be taken into account when treating patients and their next of kin and should also be a subject for future research.
SVENSK SAMMANFATTNING
(SUMMARY IN SWEDISH)

BAKGRUND
Kroniskt Obstruktiv Lungsjukdom (KOL) förekommer som en av de största orsakerna till kronisk sjukdom i världen. Det är en sjukdom som ökar och orsakar stora hälsoproblem. KOL karaktäriseras av en långsam progression med en inskränkning av luftvägarna och är inte helt reversibel, varken spontant eller med läkemedel. Läkemedel anses enbart ha en symptomlindrande effekt och kan minska antalet försämringsperioder. Det enda som visat sig effektivt och som kan förbättra funktionen i det dagliga livet är KOL-rehabilitering. KOL orsakas till största delen av tobaksrökning. I Sverige är prevalensen i befolkningen beräknad till 14% från en ålder av 45 år och över. Diagnosen KOL baseras på spirometri och är indelad i fyra svårighetsgrader där stadium 1 är en mild form och stadium 4 är mycket svår. Tidigare hade fler män än kvinnor utvecklat KOL men i takt med rökningens utbredning så beräknas fler kvinnor bli drabbade och de angrips värre än män. KOL kommer alltså att kräva mer av sjukvården och då också primärvården vilket innebär att primärvården måste vara förberedd för att vårda patienter med KOL och deras närstående.


I tidiga stadier kan KOL uppstå utan några symtom. De första symptomen är ofta hosta och slem sedan ökas symtomen med att ge andnöd, först tillsammans med fysisk aktivitet och i senare stadier andnöd även i vila. Försämringsperioder är förödande och har en påverkan på det dagliga livet med minskad funktionell kapacitet och livskvalitet. Försämringsperioderna orsakas främst av övre luftvägsinfektioner och leder till en försämring av lungfunktionen samt ökad andnöd.

Patienternas upplevelser
Patienter har i studier beskrivit andnöd som det värsta symtomet och upplevs stressande, skrämmande och påverkar det dagliga livet genom be-
gränsningar i aktiviteter, brist på energi, begränsad social funktion, sömnbesvär och ångest. Den psykologiska hälsan har beskrivits påverkad med ångest och depression samt en känsla av att vara beroende av andra. Patienter med KOL beskriver en känsla av skam över att de har orsakat sjukdomen själva genom sin rökning. De upplever dessutom en besvikelse över en oförstående sjukvård och söker inte gärna hjälp förrän det absolut behövs, vilket är allvarligt då de uppmanas att söka tidig hjälp vid en försämringperiod. En begränsad kapacitet till ett socialt liv har beskrivits vilket resulterade i att relationen till andra försämrades och de kände sig isolerade. Även relationer i familjen kunde vara förändrade. Problem med näringsstillståndet förekom och beskrevs som svårigheter med att handla mat, laga mat och äta.

Närståendes upplevelser
Närstående har i studier beskrivit att de är påverkade av patientens KOL. Att leva med en patient med KOL beskrevs som en ökande fysisk och känslomässig börda ofta utan socialt stöd. Patientens sjukdom kunde negativt påverka kommunikationsförmågan, vanskapen och närheten till varandra. Närstående upplevde att de inte hade tid att tänka på sin egen hälsa. De har uttryckt att de ville ha mer stödning från sjukvården särskilt mer information om sjukdomen och råd hur de skulle kunna hjälpa patienten vid ökad andnöd och försämringperioder då det upplevdes mycket stressande även för den närstående. I en studie konstateras att närstående har ett stort inflytande över att hjälpa patienten att hantera ångesten samt minska antalet sjukhusbesök.

KOL-rehabilitering
Syftet med KOL-rehabilitering är att minska syftomen, öka den funktionella förmågan och patientens delaktighet i vården. KOL-rehabilitering fokuserar på fysisk aktivitet men inkluderar även patientundervisning till egenvård och livsstilförändringar. I studier har patienterna med KOL beskrivit att det var viktigt med gruppen och värdefullt att få lära sig egenvård. De kände att det fått möjlighet att ta kontroll över livet och sjukdomen samt fått en ny identitet; att leva med KOL. I sjukhusmiljö är det väl känt att KOL-rehabilitering ökar funktionell kapacitet och livskvalitet samt minskar antalet försämringperioder, men det finns få vetenskapliga studier från primärvården.

Sjuksköterskeledd astma/KOL-mottagning
I Sverige har ungefär 50% av vårdcentralerna sjuksköterskeledd astma/KOL-mottagning. De utreder för diagnoserna astma eller KOL samt

**Lärande och patientundervisning**


**Problemformulering**


Det är väl känt att KOL-rehabilitering ökar funktionell kapacitet och livskvalitet samt minskar antalet försämrensperioder men detta har inte undersökt i primärvården i någon större utsträckning. Djupare kunskap om patientens erfarenheter om KOL-rehabilitering behövs för att vidare kunna utveckla strukturerade program i primärvården.

Närstående har en tung börda i livet tillsammans med en patient med KOL. Ingen kunskap finns idag för hur närstående påverkas av att patienten genomgår KOL-rehabilitering eller hur de ska stöttas samt att undvika hälsoproblem hos dem. Djupare kunskap behövs.
Det finns ett behov av mer kunskap om hur patienter med KOL och deras närstående kan vårdas i primärvården för att kunna möta det ökande behovet i primärvården.

SYFTE
Det övergripande syftet var att modifiera, utvärdera effekter såväl som att beskriva erfarenheter av ett sjuksköterske-lett multidisciplinärt program för KOL-rehabilitering i primärvården för patienter med KOL och deras närstående.

Design
Studierna har genomförts med kvalitativa intervjustudier (I, III-IV) och en quasi-experimentell interventionsstudie (II).

Intervention

METOD
I studie I ingick 12 KOL-sjuksköterskor som intervjuades med semistrukturerade frågor om deras upplevelse av undervisning till patienter med KOL och hur de ville utveckla sin undervisning. Data analyserades med kvalitativ innehållsanalys.


I studie III och IV ingick 20 patienter med KOL som genomförde KOL-rehabiliteringen och 20 närstående. De intervjuades med semistrukturerade frågor angående sina erfarenheter av det sjuksköterskeledda...
multidisciplinära programmet. Data analyserades med kvalitativ innehållsanalys.

Studierna II-IV godkändes av Etiska prövningsnämnden. Vid tiden för genomförandet av studie I krävdes inget etiskt tillstånd för den typen av studier. Alla studier (I-IV) innehöll ett informerat samtycke med formulering om frivillighet att delta.

RESULTAT

Studie I
De intervjuade KOL-sjuksköterskorna pendlade mellan osäkerhet och säkerhet i sin patientundervisning. Om de fick stödning resulterade det i säkerhet och de kunde utveckla sin patientundervisning. Avsaknad av stödning resulterade i en känsla av osäkerhet och de upplevde det svårt att utveckla sin patientundervisning. Sjuksköterskorna ville ha mer utbildning, mer tid, mer samarbete med de andra professionerna på vårdcentralen och mer struktur på sin patientundervisning.

Studie II
Resultatet visade att det inte blev några skillnader mellan grupperna avseende 6-minuters gångtest och livskvalitet. Antalet försämringssperioder minskade i interventionsgruppen och ökade i kontrollgruppen efter ett år. Denna skillnad var statistiskt säkerställd. Inom interventionsgruppen förbättrades både livskvaliteten och 6-minuters gångtest signifikant. Även inom kontrollgruppen ökade 6-minuters gångtest som säkerställdes statistiskt, men inte livskvaliteten.

Studie III
Patienternas erfarenhet av programmet var att de lärde sig att leva i sin egen takt och hade fått hjälp att ta kontroll över livet. De hade fått insikter om sina begränsningar. En del tyckte inte att programmet berörde dem, de hade redan hittat sina strategier för hur de skulle hantera sitt liv. Alla hade en närvarande rädsla för sin sjukdom KOL. De som var rädda från början blev dock något lugnare medan de som inte var rädda kunde bli mer rädda efter att de fått kunskap. Livet var överskuggat av rädsla för en osäker framtid.

Studie IV
Närståendes erfarenheter var att sjukdomen KOL fortfarande överskuggade deras liv, trots att patienten genomgått KOL-rehabiliteringen. De beskrev att livet hade sina positiva sidor men de levde med en känsla av

Slutsatser


Resultatet kan användas i primärvården och önskvärt är att KOL-rehabilitering kan få en fortsättning. Eftersom antalet försämningsperioder minskade så kan det förhindra en försämring av sjukdomen och bespara patienten onödigt lidande med sänkt livskvalitet och funktionell kapacitet i det dagliga livet. KOL-rehabilitering har en styrka i att förändra livsstil och att förbättra patientens dagliga liv. Men undervisning i grupp passar inte alla patienter med KOL, en del är mer i behov av individuell undervisning. KOL-sjuksköterskorna och deras team är i behov av mer undervisning i pedagogik, inte bara vad som ska läras ut utan också hur. Det måste bere-
das möjligheter till det både i internutbildning och via universitetsstudier. Sammanfattningsvis visar resultaten att primärvården kan göra en god insats för patienter med KOL speciellt eftersom personalen inom primärvården är generalister avseende den komplexa bilden av multisjuklighet.
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ANN-BRITT ZAKRISSON
Managing COPD in primary health care

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