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I HAVE TO QUIT! FACTORS THAT INFLUENCE QUIT ATTEMPTS IN SMOKERS WITH COPD

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I have to quit! Factors that influence quit attempts in smokers with COPD

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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*When I ask you to listen to me and you start giving advice, you have not done what I asked.
When I ask you to listen to me and you begin to tell me why I shouldn't feel that way, you
are trampling on my feelings.*

*When I ask you listen to me and you feel you have to do something to solve my problems,
you have failed me, strange as that may seem.*

So please, just listen and hear me.

By Leo Buscaglia

*All things are possible until they are proved impossible – and even the impossible may only
be so, as of now*

By Pearl S. Buck 1959

ABSTRACT

Background and aim: The most effective treatment for patients with chronic obstructive pulmonary disease (COPD) is to quit smoking. Despite this, many patients with COPD continue to smoke. In Sweden, most patients with COPD are treated in primary health care settings. The general aims of the doctoral project presented in this thesis were to describe the care of patients with COPD from the perspective of district nurses and to describe factors that can negatively influence COPD patients' smoking cessation efforts. A further aim was to develop a valid and reliable instrument to assess difficulties smokers with COPD deal with, and that would be useful in dialogues about smoking that are held in a clinical setting.

Material and methods: This mixed method thesis project included 4 studies. Study I used phenomenographic approach to analyze data from interviews with 20 nurses responsible for the care of patients with COPD in primary health care settings. Study II used grounded theory method to analyze data from interviews with 14 patients with COPD (smokers and former smokers) and develop a theoretical model describing the process of trying to quit smoking. The results of Study II were used to construct the Trying to Quit smoking (TTQ) instrument, and Study III used exploratory factor analysis on data from 63 smokers with COPD to investigate the psychometric properties of the TTQ. In Study IV, 109 smokers with COPD answered the TTQ at baseline and after 3 months. Unconditional logistic regression was used to analyze the association between the TTQ scale and making a quit attempt, reducing the intensity of smoking and achieving complete abstinence.

Results: Study I identified 4 perceptions of care of patients with COPD among nurses and 2 perspectives on care: task-oriented and individual-oriented. Nurses expressed feelings of frustration and powerlessness in their encounters with patients with COPD who smoked and could not quit smoking. Study II found that patients with COPD can develop pressure-filled mental states in the process of quitting smoking. These can be burdensome and patients use a variety of constructive or destructive pressure-relief strategies to find relief. The constructive pressure-relief strategies led to success in quitting or continued efforts to quit. The destructive pressure-relief strategies could lead to loss of hope and resignation to continued attempts in quitting. The TTQ was developed to measure these mental states and strategies. The final instrument includes three factors 1) development of pressure-filled mental states, 2) use of destructive pressure relief strategies, and 3) ambivalent thoughts when trying to quit smoking. Studies III and IV found that the TTQ is a reliable instrument. It can be used to predict factors that have a negative impact on quit attempts in this group of patients, especially pressure-filled mental states in patients ready to try to quit and ambivalent thoughts in patients not ready to try to quit.

Conclusion: Care for patients with COPD depended of whether the patient met, a task-oriented or individual-oriented nurse. Both the theoretical model "The process of trying to quit smoking" and use of the TTQ contributes to a better understanding of the negative experiences of some patients with COPD in the process of trying to quit. The model and instrument can help health care providers individualize smoking cessation counseling.

Moreover, patients' own awareness of these states and strategies may facilitate their efforts to quit.

Keywords: chronic obstructive pulmonary disease, primary health care, interviews, phenomenography, grounded theory method, exploratory factor analyses, smoking cessation, clinical research, TTQ.

LIST OF SCIENTIFIC PAPERS

This thesis is based on following original articles, referred to in the text by their Roman numerals.

- I. Lundh L., Rosenhall L., Törnkvist L.
Care of patients with chronic obstructive pulmonary disease in primary health care
Journal of Advanced Nursing 2006; 56 (3), 237-246
doi:10.1111/j.1365-2648.2006.04027.x
- II. Lundh L., Hylander I., Törnkvist L.
The process of trying to quit smoking from the perspective of patients with chronic obstructive pulmonary disease
Scandinavian Journal of Caring Sciences 2012; 26: 485-493
doi: 10.1111/j.1471-6712.2011.00953.x
- III. Lundh L., Alinaghizadeh H., Törnkvist L., Gilljam H., Galanti MR.
Measurement of factors that negatively influence the outcome of quitting smoking among patients with COPD: psychometric analyses of the Trying To Quit Smoking instrument
Nursing Open 2014 Doi: 10.1002/nop2.4
- IV. Lundh L., Alinaghizadeh H., Törnkvist L., Gilljam H., Galanti MR.
The Trying To Quit Smoking (TTQ) questionnaire– a promising instrument for predicting smoking cessation among patients with COPD
Manuscript.

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LIST OF ABBREVIATIONS

COPD	Chronic obstructive pulmonary disease
FEV	Forced expiratory volume
PHCC	Primary health care center
RN	Registered nurse, both district nurse and general nurse
GTM	Grounded theory method

PREFACE

The issues and research questions in this thesis were developed during my work in primary health care centers (PHCCs). As nurse and later a district nurse, I always have been interested in health promotion and prevention. I realized quite early in my work at PHCCs that it was inspiring and important to support people in quitting smoking. It could be a real challenge to help those who have the most difficulties quitting; for example, people with COPD. In 1989 I started my first smoking cessation group for patients at the PHCC. In the years since then, I have continued to work with smoking cessation counseling. In the beginning of 2000, I was given the opportunity to be part of several trials testing new pharmacotherapy for smoking cessation at the Centre for Tobacco Prevention in Stockholm. In 2003, I was hired by the Centre for Tobacco Prevention and made responsible for coordinating courses in smoking cessation counseling for health care providers. Since 2009 I have worked with development and implementation of continuing education in primary health care for district nurses and nurses and with health promotion and disease prevention at the Centre for Family Medicine.

In 2004, The Swedish National Board of Health and Welfare published national guidelines for the care of patients with COPD [1]. In 2003, I was given the opportunity to interview nurses caring for patients with COPD and asthma about their perspectives on this care. Later I also interviewed patients with COPD about how they deal with the need to quit smoking because they have been diagnosed with COPD.

Issues, such as smoking cessation counseling, are multidisciplinary. In this thesis, however, I have approached these issues from the nursing perspective.

The intention behind this project was to contribute to the knowledge and understanding of the feelings persons with COPD have about smoking to the knowledge and understanding of nurses' perspectives on the care of this group of patients. I hope the results will help nurses better understand the difficulties faced by people with COPD when they try to quit smoking. Hopefully, the information will also lead to better-tailored support for smokers with COPD who are participating in smoking cessation counseling. Equal care does not mean giving same care to all people; it means different and appropriate care to all people.

1 INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) is currently, the fourth leading cause of death worldwide [2]. Nine to ten percent of people older than 40 years have COPD [3], and the prevalence is increasing as smoking frequencies rise and the population ages [4]. Most patients with COPD are treated at primary health care centers (PHCCs). At many PHCCs, nurses keep pace with current knowledge about chronic diseases like diabetes [5, 6], chronic pain [7] asthma, and COPD [8]. Some even hold nurse-led clinics, most commonly about patients with diabetes and asthma/COPD [9, 10]. Researchers have found that if specialized nurses in primary health care pay special attention to the care of patients with COPD, the number of exacerbations' decrease [11].

In Sweden, 50 % to 80 % of PHCCs report that they have an asthma/COPD clinic at the center [12]. One of the two main criteria recommended by Swedish national guidelines for an asthma/COPD clinic is that it should be led by a primary care nurse specialized in respiratory diseases. This nurse specialist must work at least one hour per week per 1000 patients registered at the PHCC. The second criterion is that the clinic must have the support of a specially trained general practitioner [1].

The main tasks of the asthma/COPD nurse are to perform lung function tests, offer smoking cessation counseling, and provide educational and self-management support to patients with COPD [13]. A study of 42 PHCCs in Sweden found that if nurses have enough time, they assess lung function tests (spirometry), has more frequent contact with each patient, and document current smoking habits of high quality. Less time resulted in the examination of fewer patients with spirometry and fewer smoking habits records [14]. Self-management education for patients with COPD is associated with improved health-related quality of life, reduction in respiratory-related hospital admissions, and improvement in dyspnea [15]. One of the most important aspects of the treatment of patients with COPD is supporting smoking cessation [2]. However, even if patients receive this support, many continue to smoke [16].

2 BACKGROUND

2.1 LIVING WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Just being diagnosed with COPD seems to be a breakdown of life [17]. Living with breathlessness is one of the most prominent and threatening symptoms of the illness [18]. This breathlessness can lead to isolation, and patients describe this as feeling like they only “exist” rather than “live” [19]. Feelings of shame and embarrassment can be manifested in social isolation and stigma [19-22]. People with COPD, especially in the severe stages, are at high risk of loss of social support [23]. Depression is also common among people with COPD [24, 25].

Having COPD and symptoms like breathlessness can be experienced as exhausting because of a constant struggle and fight to breath and can lead to limitation of activities [26]. The unexpected change to an acute illness can be a life-threatening situation [18] and requires constant planning and balancing to incorporate the demands of COPD into daily life. Dyspnea, which involves not only breathlessness but also fatigue, is defined as a subjective, unpleasant symptom that incorporates total body feelings ranging from tiredness to exhaustion [27]. About 50 % of patients with COPD experience fatigue so severe that it results in functional limitations and worsened health [28].

Malnutrition is also common among people with COPD, both in those who are underweight and those who are overweight [29]. In particular, low body mass index (BMI) is a risk factor for mortality in people with severe COPD [30]. However, recent studies report that overweight has become more common than underweight among people with COPD [31]. Overweight can lead to decreased lung function, respiratory symptoms, and cardiovascular disease [32, 33]. People with high BMI can still be malnourished or undernourished [34].

People with COPD are often older, male, manual workers, and socioeconomically deprived than those not diagnosed with the disease [35]. There are some gender differences in the clinical symptoms of persons with COPD. Women have more dyspnea and less phlegm production than men. More women report their health as fair to poor than men who instead report their health as fair. Studies have also reported differences in the comorbidities experienced by men and women. Women demonstrate higher levels of anxiety and depression, whereas men report a higher prevalence of cardiovascular comorbidity and diabetes mellitus. The reasons for these differences are not clear [36].

COPD is a progressive and lifelong disease, and people with COPD use different coping strategies to achieve well-being [37]. Coping has been defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" [38](p 141). The most common coping strategies reported among people with COPD are problem-focused, emotion-focused, and avoidance-focused [39, 40]. The problem-focused strategies are characterized as active and use positive thinking in problematic situations, which usually results in better

psychological well-being. People who employ emotion-focused strategies use anxiety, anger, and helplessness to reduce threat. Avoidance-focused strategies involve the use of defensive reappraisal or behavioral strategies to avoid threats [41]. The various coping strategies are commonly used by people who are deciding whether or not to quit smoking [42].

2.2 CHRONIC OBSTRUCTIVE PULMONARY DISEASE

COPD was first mentioned in 1964 by Mitchell and Filley, who described COPD as including emphysema, bronchitis, asthmatic bronchitis, and chronic bronchitis [43]. COPD has grown into a global health problem, and the prevalence of the disease is still increasing. Today, COPD is one of the leading causes of morbidity and mortality worldwide [2]. In Sweden 6 % to 8 % of the population is diagnosed with COPD [44]. When COPD is defined in accordance with the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines, the prevalence of mild COPD in Sweden is 8.2 %; of moderate COPD, 5.3 %; and of severe COPD, 0.7% [2, 45]. Fifty percent of older smokers develop COPD [44]. Mortality caused by COPD is increasing worldwide, including in Sweden, where death rates have risen by 50 % for women and 2 % for men during the past 10 years [46, 47]. The prevalence of and morbidity caused by the disease are greatly underestimated, however, because the disease is usually not diagnosed until it is clinically apparent and moderately advanced [2].

GOLD defines COPD as “a common preventable and treatable disease characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients” [2] (GOLD 2012, p 2).

People with COPD do not recover normal lung function because of the irrevocable and progressive condition of the disease. Early symptoms associated with COPD are cough and phlegm, which can delay diagnosis because they can also be interpreted as normal. Furthermore, at the outset of the disease, the cough precedes airway obstruction and symptoms of breathlessness during physical activity, and later on, in severe stages, even during rest [2].

The diagnosis is easy to make by measuring lung function with spirometry. The results are divided into four stages of severity, ranging from stage 1 (mild) to stage 4 (very severe) [2] (Table 1).

Table 1. Classification of severity of airflow obstruction in people with COPD

Stage	Severity	Limitation in COPD patients with forced expiratory volume for 1 second/forced vital capacity ($FEV_1/FVC < 0.70$)
Gold 1	Mild	$FEV_1 \geq 80\%$ predicted
Gold 2	Moderate	$50\% \leq FEV_1 < 80\%$ predicted
Gold 3	Severe	$30\% \leq FEV_1 < 50\%$ predicted
Gold 4	Very severe	$FEV_1 < 30\%$ predicted

Abbreviations: COPD, chronic obstructive pulmonary disease; FEV_1 , Forced expiratory volume for 1 second.

2.3 COPD AND SMOKING

Smoking is the major cause of developing COPD and of the continued progression of the disease. Despite the importance of quitting smoking, many people with COPD continue to smoke [35, 48]. In Sweden, more than half continue to smoke after a diagnosis of COPD, but there are large differences in the prevalence of continued smoking in different parts of the country [49, 50]. Only one third of smokers with COPD are offered support, and 18 % have quit 1 year later [49]. Some people with COPD seem to see their health care provider's advice to quit smoking as routine and not directly related to the diagnosis of COPD [51]. It seems that smokers have varying beliefs about the causal link between smoking and COPD. Sometimes they believe that family history, exposure to pollution, and age play more of a role in causing COPD than smoking [52, 53] and are unaware that continued smoking will worsen their COPD [54].

Dependence on cigarette smoking is complex and is described as caused by both addictive behavior and a neurobiological mechanism. Transportation of nicotine to the brain is very rapid, and within 10 seconds of inhaling tobacco smoke, the smoker gets a response from the reward system. Subjective rewards may include feelings of increased arousal, less fatigue, and stress relief [55]. On the other hand, typical withdrawal symptoms include fatigue, drowsiness, negative mood states, anxiety, and irritation [56]. Some of these symptoms, such as fatigue and anxiety, are also common in patients diagnosed with COPD [57, 58]. The International Classification of Diseases (ICD-10) and Diagnostic and Statistical Manual version IV (DSM IV) define nicotine addiction as "a relapsing brain disorder characterized by loss of control over smoking and with negative impact on daily function" [59, 60]. Symptoms of dependence include the development of tolerance to nicotine, smoking more cigarettes,

and continuing to smoke despite harmful effects and knowledge of these effects [60]. The addictive behavior is also related to a number of known nicotine cues such as the sight of a packet of cigarette [55].

People with COPD are at increased risk of developing depression [61]. Smoking cessation can reduce the risk of depression, anxiety, and stress and improved mood and quality of life compared with continuing to smoke [62]. Studies have also shown that smokers with COPD have higher levels of nicotine dependence and smoke a larger average number of cigarettes than smokers without COPD [35, 63]. Exposure to smoking cues (such as living with smokers) and severe withdrawal symptoms can negatively affect the outcome of a quit attempt [64]. Some smokers endorse the belief that damage from smoking, especially in people with COPD, is too advanced to make quitting worthwhile [65].

Despite knowing about the harm cigarettes cause, many patients with COPD continue to smoke because in some ambiguous way, smoking gives them feelings of both control and company [67].

2.4 MANAGING CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Some of the most important strategies for managing COPD are early diagnosis, smoking cessation, physical exercise, vaccinations, patient education, and pharmacological treatment [2]. One effective treatment is working with a pulmonary rehabilitation team in combination with medical therapy. This treatment includes exercise training, nutritional and smoking cessation counseling, education about the lung disease and how to manage it, energy-conserving techniques, breathing strategies, psychological counseling, and/or group support. A pulmonary rehabilitation team may consist of doctors, nurses, and specialists (specialists can include respiratory therapists, physical therapists, occupational therapists, dieticians or nutritionists, and psychologists or social workers) [8]. Far from all PHCCs have pulmonary rehabilitation teams [9]. Instead, one or two nurses at the PHCC are usually responsible for the nursing care of persons diagnosed with pulmonary diseases [9]. Evaluations conducted in the Swedish PATHOS study found that the care of patients with COPD can be both cost-effective and better if nurses and general practitioners collaborate [9].

2.4.1 Education for patients with COPD

Education for patients with COPD is often focused on self-management of COPD, increasing the patient's knowledge about the disease, and helping the patient adopt positive health-seeking behaviors; for example, quitting smoking. It also includes recommendations on how to monitor and manage symptoms. When problem then occur, the patients have to solve them, respond to changes, and manage the impact of the disease in daily life. Collaboration between individuals and health providers is clearly needed to manage all this. Collaboration between primary, secondary, and tertiary care is also needed to help patients access supportive resources and navigate through the health care system [68].

2.4.2 Smoking cessation

Smoking cessation is the single most effective way to reduce the risk of developing COPD and is the most important treatment for the disease [69, 70]. It is also the most cost-effective and important way to affect the outcome at all stages of the disease [71, 72].

Smoking cessation interventions are of two types, psychosocial and pharmacological. The most effective interventions, especially for people with COPD, seem to be those that combine both types [73].

The Lung Health Study, a randomized controlled study, which included nearly 6000 smokers with early stage of COPD, confirmed that smoking cessation is the only proven way to slow down the development of COPD by preventing further deterioration of lung function. The researchers could see that the decline in forced expiratory volume in 1 second (FEV1) was reduced, sometimes to same level as non-smokers [74]. The Lung Health Study program included: a) a strong message to quit smoking and explanations of the risks of continuing to smoke when diagnosed with COPD; b) 12 smoking cessation sessions (group sessions), which included an explanation of behavior modification techniques, use of nicotine replacement therapy at no cost; and c) support from spouses. The control group were offered usual care [75].

The Swedish National Guidelines for Disease Prevention issued by The National Board of Health and Welfare recommend advanced smoking cessation counseling for all smokers with chronic diseases. Furthermore, these recommendations advocate counseling tailored to the person's age, health, and risk level and multicomponent interventions, such as a combination of counseling and pharmacotherapy. The counseling should also be theory-based; for instance, it should employ cognitive behavioral therapy and/or motivational interviewing. Like international guidelines [76], Swedish guidelines also recommend pharmacological treatment for persons with chronic illness like COPD [77]. Despite all these recommendations for clinical help, few health care providers really assist patients in quitting [49]. A meta-analysis of 42 studies indicates that smoking cessation advice given by nurses is effective, especially if it is given by nurses whose main role is health promotion or smoking cessation. It should be noted that the studies in the meta-analysis covered smokers in general, not just those with COPD [78]. Furthermore, researchers have also reported that the proportion of patients with COPD who use smoking cessation agents is low, especially patients with low incomes [79].

Counseling and pharmacological therapy, combined with adequate support, can increase the quit rate by 50 % to 60 % during the first 3 months after diagnosis with COPD [80]. However, after 12 months follow-up the risk of relapse is almost 50 %. Thus, the proportion of people still abstaining from smoking 1 year after quitting is at best 25 % to 35 % [76, 81]. The simple advice to quit, given by a physician, results a quit rate of about 2 % to 3 %, but has no place in COPD care [82]. Face-to-face counseling has a dose-response effect based on the time and number of sessions, among other factors [83]. Relapses can also decrease self-

efficacy (the belief that you can accomplish your goals), which can lead to negative effects [84]. Studies have found that existing treatments and interventions for people in the relapse recovery phase are largely ineffective [64]. Feelings associated with low self-efficacy and difficulties quitting smoking are common among smokers diagnosed with COPD [85, 86], as are feelings of guilt and shame [20, 67]. It is also common for the lives of smokers with COPD to revolve around attempts to quit [86].

Ambivalence is a normal psychological state for people in a decision-making process; for example, in the process of quitting smoking. Researchers have also found that ambivalence can increase the risk for relapse [87]. Smoking cessation counseling is usually based on cognitive behavioral therapy [88]. In recent years, motivational interviewing has become a rather popular method, particularly for helping resolve people's ambivalence to health behavior change [89]. This method, developed by Miller and Rollnick in the 1980s and 1990s, is a form of collaborative conversation for strengthening a person's own motivation to change [89].

2.4.3 Questionnaires that measure different aspects of smoking cessation

Because of the complexity of cigarette dependence, researchers have developed questionnaires that measure different aspects of dependence. Among the most common questionnaires used to measure nicotine dependence are Fagerströms Tolerance Questionnaire (FTQ) [90] and its shorter form, Fagerströms Test for Nicotine Dependence [90, 91]. In particular, these 2 questionnaires are widely used in research and by health care providers deciding which kind of nicotine replacement therapy to prescribe to patients trying to quit smoking. The reliability and validity of FTQ has been questioned in recent years. The reason for this is the dichotomous response alternatives, which force the respondent to answer yes or no. In later studies, the response option has been changed to a 4-point Likert scale, which improved scale reliability and enhanced convergent validity. After the revision, researchers found a stronger association between responses and smoking outcomes than found when the original instrument was used [92]. The shorter form of Fagerströms Test for Nicotine Dependence is frequently used today, both in research and clinical settings.

On the other hand, smoking is not only a matter of nicotine dependence. The self-administered Cigarette Dependence Scale was developed [93] to measure behavior-related dependence. The questions on the Cigarette Dependence Scale are designed to gather information about main aspects of dependence as defined by the DSM-IV and ICD-10 [59, 60]. These are: compulsion, withdrawal symptoms, loss of control, time allocation, neglect of other activities, and persistence despite harm [59, 60]. Etter found that the CDS is a reliable and valid tool for measuring cigarette dependence over time [94].

Since the 1970s, several instruments have been developed to measure withdrawal symptoms during smoking cessation and are mainly used in research rather than clinical settings. These include the Cigarette Withdrawal Scale [94], the Minnesota Nicotine Withdrawal Scale [95], the Shiffman-Jarvik Withdrawal Scale [96], the Smokers Complaint Scale and the Mood and

Physical Scale [97]. All scales cover the main elements of the DSM-IV and ICD-10 definitions of tobacco withdrawal.

Self-efficacy the extent of peoples' belief in their own ability to complete tasks and reach goals is important for all changes in health behavior [98]. The Smoking Abstinence Self-efficacy Questionnaire was developed to assess self-efficacy in smoking cessation. It describes social and emotional situations as risk factors for relapse and a study suggests it is a valid and reliable short questionnaire [99].

To measure expectations about smoking and smoking cessation, Copeland et al. developed the Smoking Abstinence Questionnaire (1995). The questionnaire covers a variety of emotional aspects and of most known expectations about the process of quitting. Fifty-five items are included in 10 scales: negative affect reduction, stimulation/state enhancement, health risks, taste/sensorimeter manipulation, social facilitation, appetite/weight control, craving/addiction, and negative social impression. The instrument was developed for use with heavier and dependent smokers in research situations [100]. Because the Smoking Abstinence Questionnaire is so long, Rash and Copeland developed a shorter version, called the Brief Smoking Consequences Questionnaire. This the 25-item questionnaire is appropriate for use with adult heavy smokers who have significant experience with smoking or histories of extensive smoking [101].

2.5 THEORETICAL FRAMEWORK

The ontological bases of this thesis are caring science, the knowledge generated by caring science, and an interest in the whole person and his or her needs [102]. Clinical nursing practice offers a perspective on stress and coping in health and illness different from a purely psychological or biomedical view and even different from that of behavioral medicine. An expert nurse focuses on lived experience in health and in stressful situations [103]. Such a phenomenological definition of health should be based on an integrated view of mind, body, and spirit and should focus on possibilities [103].

2.6 PERSON-CENTERED CARE

Person-centered care is a central concept in this thesis. In person-centered care, the caregiver focuses on knowing the person behind the patient in order to engage the person as an active partner in his or her care and treatment. Person-centered care starts with partnership-building and includes sharing information, deliberation, and decision making. At diagnosis, the care team, including the patient, should evaluate all aspects of health care management, taking into account treatment options that are suited to the patient's lifestyle, preferences, beliefs, values, and health issues [104, 105]. Both patient-centered care and person-centered care are important concepts in the care of patients. Although, professionals providing both kinds of care should be required to adequately recognize patients' health problems, there are also differences between the two concepts. Person-centered care is based on accumulated knowledge of people's health problems and needs over time independent of caring for people

with a particular disease. Patients-centered care is focused on the interactions in visits that usually involve the care of persons with chronic diseases [105, 106].

2.7 THE RATIONALE FOR THIS THESIS

In Sweden, most patients with COPD are treated at PHCC and usually by nurses. The literature on how nurses care for patients with COPD, especially smokers with COPD who are treated in primary health care, is sparse. Although the nurses are important in the care of patients with COPD, there has been relatively little investigation into their work with this group of patients. To better tailor advice given to this group of patients, it is also important to investigate patients' view of this care, especially feelings and thoughts about smoking cessation. Health care professionals need clinically useful methods and instrument to help predict which patients will require more support to succeed in their attempts to quit smoking. It is also important for nurses to continue to support patients so the patients continue to try to quit smoking.

3 GENERAL AND SPECIFIC AIMS

3.1 GENERAL AIM

The general aims of the doctoral project presented in this thesis were to describe the care of patients with COPD from the perspective of district nurses and to describe factors that can negatively influence COPD patients' smoking cessation efforts. A further aim was to develop a valid and reliable instrument to assess difficulties smokers with COPD deal with, and that would be useful in dialogues about smoking that are held in a clinical setting.

3.2 SPECIFIC AIMS

The specific aims of this thesis were to:

- Describe and analyze the way a group of nurses perceived the care of patients with COPD.
- Investigate why some patients with COPD have difficulty quitting smoking and to develop a theoretical model that illuminates their difficulties in this process.
- Test the internal consistency and factor structure of a brief instrument, the TTQ, designed to identify processes that negatively influence the occurrence or the outcome of quit attempts among patients with COPD.
- Evaluate the ability of the TTQ to predict smoking cessation outcomes among smokers with COPD.

4 METHODS AND PARTICIPANTS

4.1 STUDY DESIGN—MIXED METHODS

This doctoral research project used both quantitative and qualitative data (Table 2). Data were collected between 2003 and 2013 at PHCCs in Stockholm County. In Study I, nurses were interviewed to achieve a deeper understanding of how they perceived the care of patients with COPD. In Study II, patients with COPD were interviewed to obtain a better understanding of why they have difficulties quitting smoking and to develop a theoretical model that illuminates their difficulties. Study III used the theoretical model from Study II to develop the TTQ and measure its psychometric properties. Study IV measured the TTQ's ability to predict smoking cessation outcomes among smokers with COPD. All four studies were conducted in the Stockholm region. Study I was undertaken in the southern part of Stockholm County. Studies II-IV was carried out across the whole Stockholm region. Study I involved nurses with special interest in patients who had respiratory diseases, and studies II-IV involved both nurses and smokers or ex-smokers with COPD.

Table 2. Overview of studies, participants, data collection, and data analysis in the doctoral project

Study	Study focus	Participants	Data collection	Data analysis
I	Description of how a group of nurses perceived the care of patients with COPD	Nurses working in primary health care (n=20)	Individual interviews	Phenomenographic approach
II	Illustration, in a theoretical model, of COPD patients difficulties when trying to quit smoking	Patients with COPD who smoke or had quit smoking after diagnosis (n=14)	Individual interviews	Grounded theory method
III	Test of internal consistency and reliability of the TTQ	Persons with COPD who smoke (n=63)	Questionnaire	Student t-test Chi square test Fischer's exact test Chronbach's alpha Exploratory factor analysis
IV	Test of the ability of the TTQ to predict smoking cessation	Persons with COPD who smoke (n=109)	Questionnaire	Student t-test Chi square test Unconditional logistic regression

Abbreviations: COPD, chronic obstructive pulmonary disease; TTQ, Trying to Quit smoking instrument.

4.2 STUDY I

4.2.1 Phenomenography

Phenomenography was developed in the beginning of 1970s by educational researchers Ference Marton and Lennart Svensson. More recently, the phenomenographic approach has been adopted in nursing research [107]. Marton and Svensson [108] define phenomenography as describing, analyzing, and understanding human experience and persons' different ways of reasoning (how) about a phenomenon, which delimits what they interpret as the meaning of the phenomenon (what). These aspects are interdependent and should not be separated [109]. To understand and cope with the world, people develop experiences and knowledge. In phenomenographic studies, the content identified in interviews is about this knowledge [109-111].

Study I used a phenomenographic approach to obtain a deeper understanding of how nurses care for patients with COPD. In this study, the “what” aspect was the care of patients with COPD and the “how” aspect was nurses' perceptions of the care provided to patients with COPD in primary health care.

4.2.2 Settings and participants

Nurses, who were members of a southwestern Stockholm network of nurses with special interest in patients with respiratory diseases, were invited to take part in the study in 2003. A total of 22 nurses were eligible to participate and received a letter with information about the study. They were contacted within 10 days by telephone, and the time and place of the interview were arranged. Two nurses cancelled participation in the study because of heavy workload. Information about the study was also sent to the nurses' manager. Twenty nurses were included in the study; they had worked as nurses for between 2 and 37 years. Their experiences of patients with asthma and COPD varied in duration (mean=5 years). More than half the participants were specially trained to care for patients with asthma and COPD, and the participants worked approximately 7 hours a week with this group of patients.

4.2.3 Data collection

Data were collected through individual semi-structured interviews at the nurses' workplaces. The interviews were conducted as dialogues that lasted 45-60 minutes and guided by the nurses' reflections and narratives [112]. An interview guide was used. The guide consisted of open-ended questions about the nurses' perceptions of asthma and COPD as a disease and their roles in the care of patients with asthma and COPD. The nurses were first asked to describe the care of patients with asthma and then the care of patients with COPD. This was a deliberate strategy to prompt them to differentiate their experience of the care of the two groups. To obtain a deeper understanding of the phenomenon of the care of patients with asthma and COPD, the nurses were encouraged to explain further and give examples. All interviews were audio-recorded and transcribed verbatim.

4.2.4 Analysis

Before the phenomenographic analysis commenced, we analyzed how the nurses defined and identified patients with COPD. This was done to ensure that all nurses were referring to the same group of patients as having asthma or having COPD. Phenomenographic analysis consists of 4 steps [108-110, 113-115] and starts with reading and re-reading all the interviews [108]. Thus, in the first step, each interview was read to gain a sense of the interview as a whole, and the focus was placed on the predominant, overall impression gained during reading. In the next step, the nurses' perceived experience was identified and separate perceptions began to appear. This process is called condensation. Altogether, 212 statements formed the basis for analyzing the nurses' varied perceptions of the phenomenon "care of patients with COPD." In the third step, the statements were first grouped into descriptive categories and then into subcategories. In this way an overall view of the different descriptions was formed and links between them identified. The fourth step, focused on the relationship between the descriptive categories and each transcript as a whole. This particular outcome captures the nurses' perceptions of the care of patients with COPD. An example of a perception was that care of patients with COPD consisted of creating commitment and participation via verbal expression that did not arouse feelings of guilt.

4.3 STUDY II

4.3.1 Grounded Theory

Grounded theory methods (GTM) emerged from partnership between two sociologists, Barney Glaser (an expert in quantitative methodology and text analyses)) and Anselm Strauss (an expert in symbolic interactionism) [116]. GTM is intrinsically tied to symbolic interactionism, a theory "that illuminates the relationship between individuals and society, as mediated by symbolic communication" [117]. Grounded theories, the result of a GTM study, are mid-range theories, which can be tested empirically and have the potential to provide insights and understanding that could be of great benefit to nursing practice. GTM studies may focus on behavioral concepts such as trust, resilience, caring, and coping. The key aim of GTM is the problem-focused discovery of psychosocial processes well-grounded in data. GTM is particularly useful in studies about how people make sense of their lives and health experiences [116]. It is also useful in understanding how people resolve their main concerns about making changes. GTM seeks to generate a conceptual understanding (theory) from a bottom-up analysis (inductive) of textual data [116]. There is an ongoing debate between advocates of Glaser's classic approach to GT [118] and Strauss and Corbin's more descriptive approach [119, 120]. There are now several variations of GT. In her 2006 book *Constructing Grounded Theory* [121], Charmaz focuses on writing about and understanding phenomena rather than explaining them.

GTM was chosen as research method for Study II to obtain a deeper understanding of the difficulties patients with COPD experience when trying to quit smoking. The research strategy in Study II followed the classic GT methodology presented in Glaser & Strauss (1967) [116], and developed in Glaser (1978)[118], as outlined in Hylander, 2003 [122]. The

influence of Corbin & Strauss (1998) [120], and Charmaz (2006) [121], is evident in the researchers' view on the roots of symbolic interactionism and their view that the theoretical model results from GTM analysis is a construction by the researcher [121], as are most models developed with qualitative methods in care sciences [124, 125].

4.3.2 Setting and participants

The study was carried out at PHCCs in Stockholm County, Sweden, from 1 January 2005 through 1 February 2007. To recruit patients with COPD, nurses at 5 PHCCs were asked to select the first 2 or 3 patients they met during a regular appointment at the PHCC. The nurses invited the patients to participate in the study by providing them with verbal and written information about the study. The interviewer (LL) then contacted the patients who indicated that they were interested in participating. Fourteen patients with COPD agreed to participate. To be eligible to participate, patients had to have been diagnosed with moderate to severe COPD ($FEV_1 < 60\%$) at least 1 year prior to the start of the study, be a current or former smoker (that is, a smoker who quit after receiving a clinical diagnosis of COPD). The mean age of recruited patients was 72 years (47-83). Half were men, 3 patients was former smoker, and more than half had severe or very severe COPD.

4.3.3 Data collection

All but 2 participants were individually interviewed in their homes. The 2 other participants were interviewed at the PHCC. The interviews lasted between 50 and 70 minutes and were audio-recorded and transcribed verbatim. The main topics of the interviews were the patients' perceptions of their own smoking, their experiences of smoking cessation, and their experiences of interactions with professionals in primary health care. An interview guide with open questions such as "When you received the COPD diagnosis, what did you think about smoking?" and "Why do you think you have difficulties quitting?" was used. Furthermore, questions intended to facilitate the patients' reflection and understanding were included.

4.3.4 Analysis

Data collection and analysis were conducted in parallel. The researcher and co-authors consulted each other on an ongoing basis to assure adherence to the intent of the study and consensus regarding the findings. Transcribed data from each interview were coded and categorized using the constant comparison method. The participants' main concern was defined early in the analysis as "patients with COPD worried about not being able to quit and giving up." Data were coded in 3 steps: open coding, theoretical coding, and selective coding [118]. The analyses began with open, line-by-line coding to generate initial categories. Examples of these categories included *awareness*, *try again*, and *worries*. When new questions emerged, they were used in the next interviews. In the theoretical coding, the relationships between categories were analyzed and main conceptual categories were created; for example, *deciding to try*, *trying to quit*, *pressure-filled mental states*, and *pressure relief*. The theoretical model emerged during the comparative process and included theoretical codes (Figure 1).

4.4 STUDIES III AND IV

4.4.1 Setting and participants

These studies were carried out in PHCCs in Stockholm County, Sweden, from 2011 through 2013. Smokers diagnosed with COPD were recruited via PHCC nurses who were in charge of nurse-led programs for pulmonary rehabilitation. The aim was to recruit 250 patients, and we calculated that we needed 50 nurses to participate in the study in order to achieve this recruitment aim. A total of 171 nurses were invited. Sixty-three agreed to participate and were enrolled in the study. Thirty-one of these 63 nurses managed to recruit patients. Each nurse was asked to recruit 5 patients who had a diagnosis of COPD; i.e., a total of 155 patients. Patients were eligible for recruitment if they currently smoked at least weekly and were able to speak Swedish. Patients provided verbal informed consent during their regular consultations with the participating nurse. Each nurse recruited a mean of 3 (range 1 to 5) consecutive patients with COPD who smoked, and a total of 102 patients participated. Sixty-three of these 102 were in the process of trying to quit smoking and were included in the analyses in Study III (Table 3). Study IV consisted of the same population as in Study III, 7 additional patients were recruited, a total 109 patients (Table 3).

4.4.2 Data collection

During the patient's regular consultation at the PHCC, the nurses filled in the TTQ in dialogue with the patient. Prior to obtaining verbal informed consent, the nurses provided patients with a cover letter about the study and a pamphlet with information about smoking cessation. Additionally, for the purposes of Study IV, the patients completed a questionnaire on demographic factors, family situation (living alone or with a partner), date they received the diagnosis of COPD, severity of the disease, and smoking history. They also completed the Cigarette Dependence Scale, the Audit-C screening instrument for problematic alcohol use, and the Hospital Anxiety and Depression Scale.

In addition all participants received a smoking cessation pamphlet and either brief advice on smoking cessation or advanced smoking cessation counseling with several follow-ups. The nurses registered information about smoking cessation counseling provided, the time it took to complete TTQ, and the type of clinical visit (planned or unplanned visit), and whether the visit included measurement of lung function.

Table 3. Demographic characteristics and smoking habits of participants in studies III and IV

	Study III		Study IV	
	N (%)	Mean (SD)	N (%)	Mean (SD)
Gender				
Male	19 (30)		34 (31)	
Female	44 (70)		75 (69)	
Age		65 (7.8)		65 (7.7)
Education			49 (45)	
Elementary school	25 (40)		47 (43)	
Upper secondary school	33 (52)		12 (12)	
University	5 (8)			
Family situation	30 (48)		49 (45)	
Living alone	33 (52)		59 (55)	
Married/living together				
Other smokers in the environment	30 (48)		65 (60)	
Cigarettes/day		15 (6.6)		14 (8.0)
Duration of smoking (years)		45 (9.0)		45 (8.3)
Severity of the disease FEV₁ %		58 (19.1)		60 (16.9)

Abbreviations: N, number of people in the study; SD, standard deviation; FEV, forced expiratory volume in 1 second in percent

4.5 STUDY III

4.5.1 Development of the Trying to Quit Smoking instrument

The TTQ was developed on the basis of the results of Study II and the theoretical model, "The process of trying to quit smoking in patients with COPD" [66]. The model placed particular focus on patients' feelings of pressure-filled mental states during the process of trying to quit smoking. The TTQ was meant to cover the following aspects of the process of smoking cessation: 1) decision about smoking, 2) development of pressure-filled mental states, 3) strategies to manage pressure-filled mental states, and 4) feeling hope about quitting smoking and whether it felt meaningful to quit smoking. Four dimensions and 19 items that described the process of trying to quit smoking were identified on the basis of the theoretical model.

The content and face validity of TTQ were developed in several steps:

- 1) First, 4 nurses responsible for patients with pulmonary diseases (expert nurses) were asked to judge the comprehensibility of each item, the relevance of the questions, and the relevance of the response alternatives. They were also asked whether they thought the TTQ seemed to measure the target variables (i.e., difficulties that influenced a patient's attempt to quit smoking). After this assessment, some statements were rephrased.
- 2) Second, 20 smokers diagnosed with COPD were asked to rate their understanding of each TTQ item. They also rated the applicability and completeness of the questionnaire as a whole. All items except 3 were rated as easy to understand. These 3 items were rephrased.
- 3) Third, the TTQ was pretested for internal validity among 20 smokers with COPD. We analyzed 15 items to see which dimensions of the theoretical model each item reflected. This analysis led to a preliminary grouping of the questionnaire items by the themes in the theoretical model. Some adjustments were also made in the wording.

The final version of TTQ was a 19-item instrument that covered factors likely to describe the mental processes of COPD patients before and during a quit attempt. The responses to all items were provided on a 4-point Likert scale that ranged from 1 to 4 (1 = do not agree, 2 = partly agree, 3 = mostly agree, and 4 = completely agree). Before measuring the psychometric properties of the instrument, 2 items describing the process of quitting were excluded and 2 positively worded items were reversed so that they were negatively worded. Only participants defined being in the process of quitting smoking were included in the analyses (n=63).

4.5.2 Statistical analysis

Demographic data and smoking history are presented as mean and standard deviations for numerical continuous variables and as frequencies and percentages for categorical variables. Comparison between groups (men and women) was made using two-tailed t-test when the normality assumption was met. The chi-square test was used for categorical variables when more than 5 values were expected; otherwise, Fischer's exact test was used [126].

Exploratory factor analysis by using principal components methods was used to examine the structure of TTQ. The reliability of the instrument and internal consistency between items was ascertained by Chronbach's alpha and values equal or greater than 0.70 were considered satisfactory [127]. This factor extraction resulted in an unrotated factor matrix; the number of factors was decided both by using eigenvalues > 1.00 and by numbers of factors extracted account for at least 60 % of the variance. To make the results easier to interpret orthogonal varimax rotation was chosen [128]. The final 3-factor model had a cumulative eigenvalue equal to 5.86 and the total variance after rotation become 96 %. We considered the final revised factor model to be satisfactory by using the Kaiser-Meyer-Olkin measure of sampling adequacy, and Bartlett's test of Sphericity. The KMO index ranges from 0 to 1 and a score of

0.50 is considered suitable for factor analysis [129]. The results of Bartlett's test of sphericity should be significant ($p < 0.05$) for final factor model to be suitable [129]. In the revised final factor model we decided to exclude 3 items because of low loadings and high uniqueness ($>.70$). Inter-item correlation analysis was performed to compute the corrected item-total correlation of the items in the instrument, and a result of 0.30 or above was regarded as acceptable [130]. The level of significance was set at 5%.

Statistical analyses were performed using SAS version 9.3 (SAS Institutet Inc., Cary, USA).

4.6 STUDY IV

Study IV was a longitudinal observational study with same population as in Study III. Seven additional patients were recruited and data on a total of 109 smokers with COPD at baseline were analyzed. Ninety-four smokers with COPD participated in the follow up after 3 months. The outcome variables were quit attempts during the last 3 months that lasted at least 24 hours, reducing the intensity of smoking by 50 % between baseline and the 3 month follow up, and achieving complete abstinence for the 7 days prior to follow up. The nurses registered all smoking cessation events between baseline and the follow-up visit.

4.6.1 Assessment instrument

The original TTQ included 19 items about different aspects of the process of quitting smoking that were likely to negatively impact the success of a quit attempt, about intensity of smoking and about complete abstinence among patients with COPD. The TTQ used in Study III were revised into 14 items and three factors accounted for more than 90 % of the variance and total Chronbach's alpha was 0.71.

4.6.2 Statistical analysis

The demographics characteristics of the study population were presented as means + standard deviations. The Student's T-test and Chi square test were used to evaluate baseline differences.

Unconditional logistic regression was used to measure odds ratios (ORs) of quit attempts, reducing cigarettes per day by half, and complete smoking abstinence on the basis of total TTQ score. A multivariate model that included number of confounders identified via a priori knowledge (gender, education, total CDS score) and predictors (smoking cessation counseling), and outcome variables was created. Questions about patients' decisions about smoking had response alternatives "I have decided to 1) quit immediately, 2) try to quit smoking as soon as possible, 3) put off trying to quit smoking, or 4) continue to smoke. Those who chose 1 or 2 = were defined as patients ready to try to quit smoking, and those who chose 3 or 4 = as patients not ready to try to quit smoking. Separate analyses were run for these two subgroups. Unconditional logistic regression was also used to measure the association between TTQ responses and the transition from not ready to ready to try quit smoking. Statistical analyses were performed using IBM SPSS statistics 22.

4.7 ETHICAL CONSIDERATIONS

In compliance with the Helsinki Declaration ethical approvals for the four studies included in this thesis were obtained from the Ethical Committee at Huddinge University Hospital, Karolinska Institutet, Sweden and the Regional Ethic Board, Karolinska Institutet, Sweden (Study I: 184/02, Study II: 2005/134-31/1, Studies III-IV: 2008/1929-31/5)

Verbal informed consent for Study I was obtained from participating nurses, and they also received written information about the study. For studies II-IV, verbal informed consent was obtained from the participants and participation was voluntary. Nurses and patients included in the study were informed that they had the option to stop participating at any time. Interviews in studies I and II were audio recorded and transcribed verbatim. The recordings and the transcriptions are kept locked up at the Centre for Family Medicine, Karolinska Institutet, Sweden.

Patients included in Studies III-IV received written information from participating nurses about the purpose of the studies, confidentiality, and the voluntary and anonymous nature of participation. All questionnaires were collected by the nurses and returned in closed envelopes to the doctoral researcher (LL). A list of participants was kept by the nurses who recruited the patients. This list had no connection with the project.

5 MAIN RESULTS

5.1 THE CARE OF PATIENTS WITH COPD FROM THE NURSES' PERSPECTIVE (STUDY I)

Most of the PHCC patients' with COPD that the nurses cared for were older people with moderate to severe COPD. The nurses described the care they provided to this group of patients from 2 different overarching perspectives, task-oriented and individual-oriented. They also described 4 different major perceptions of the care.

Those who adopted the task-oriented perspective performed examinations and gave the patients information i.e., they engaged in one-way communication, often using checklists and not planning return visits for the patients. Nurses with task-oriented perspective worked fewer hours per week with special nurse practice in asthma/COPD than nurses with an individual-oriented perspective. They had also fewer credits in education about asthma/COPD and less experience working with this group of patients.

Those who adopted the individual-oriented perspective provided care in dialogue with the patient and focused on their relationship with the patient. The nurses with individual-oriented perspective could use a checklist but focused on patients' individual needs. These nurses communicated with patients about decisions concerning changes and actions and adopted the role of a source of security for the patients in the care process. Nurses with an individual-oriented perspective found it important to give patients the opportunity for frequent return visits so that the patient could ask questions and receive information about the diseases and treatment (Table 4).

All nurses, both those with a task-oriented and those with an individual-oriented perspective expressed feelings of frustration, powerlessness and insecurity when they met patients with COPD who continued to smoke.

5.1 THE PROCESS OF TRYING TO QUIT SMOKING FROM THE PERSPECTIVE OF PATIENTS WITH COPD (STUDY II)

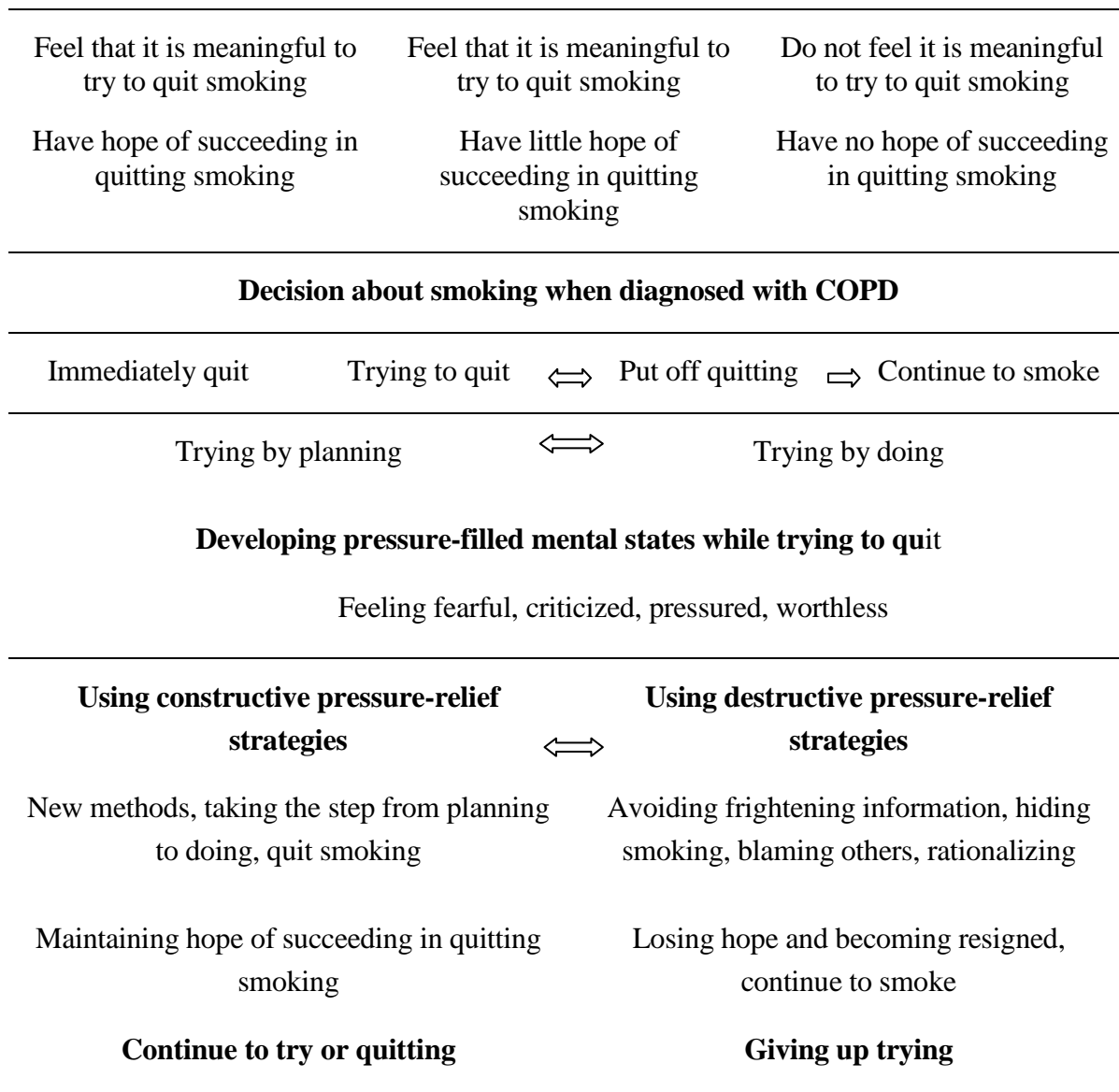
Smokers with COPD are at risk of developing pressure-filled mental states and using destructive strategies in the process of trying to quit. The theoretical model of the “process of trying to quit smoking” describes why some succeed in quitting smoking, some continue to try, and some lose hope and become resigned and stop trying to quit smoking (Figure 1). When people are diagnosed with COPD they make different decisions about their own smoking. They may decide to quit smoking immediately, to try to quit, to put off quitting or to keep smoking. Those who decided to put off quitting and continue to smoke had little or no hope of success in quitting. The decision about trying to quit smoking could lead to planning or actively making a quit attempt.

Table 4. The nurses' perception of the care of patients with chronic obstructive pulmonary disease for whom they provided care at primary health care centers

1. Creating commitment and participation	2. Educating	3. Cooperating	4. Performing clinical examinations and treatments
Using verbal expressions which do not arouse feelings of guilt; for example, when the patient was a smoker (IO perspective)	Improving and checking the patient's knowledge by giving demonstration of practical aspects of the treatment (TO and IO perspective)	Co-operation with others and pleading the patient's cause, acting as patient's advocate and looking after their interests in contacts with other health care providers (IO perspective)	Arranging and implementing technical aspect of the medical care and the nurse's task was carried out on the basis of doctor's orders (IO and TO perspective)
Establishing a good relationship and providing support, for example when talking with the patients about their life situations (IO perspective)	Using the conversation as a dialogue adapted to the individual and leaving the decision about whether to make changes to the patient (IO perspective)	Referring the patient to other care-givers and transferring responsibility to the other care-giver and not following up on progress (TO perspective)	
Creating security and inspiring hope by trying to find opportunities instead of obstacles (IO perspective).	Using different educational aids, such as pamphlets, posters and flip charts (TO and IO perspective)		
Leaving decisions about changes to the patient and respecting the patient's decision (IO perspective)	Using conversation to provide information via one-way communication by giving advice and instruction (TO perspective)		

Abbreviations: TO, task-oriented perspective; IO, Individual-oriented perspective

Figure 1. Theoretical model of "the process of trying to quit smoking"



5.1.1 Measuring pressure-filled mental states and pressure-relief strategies

Patients developed pressure-filled mental states when they made no progress from the planning stage to the doing stage, when the process of trying was protracted or when they felt criticized by family, friends or health professionals. To find relief, smokers with COPD used pressure-relief strategies that could be either constructive or destructive. The constructive pressure-relief strategies included finding and using new methods of smoking cessation, taking the step from the planning to the doing stage or just quitting smoking. The destructive pressure-relief strategies included avoiding frightening information (for example information about worsening lung function), hiding smoking from family and friends, blaming others like husband for not being able to quit or rationalizing and thinking “I am too old” or “I am not going to be better if I quit.” Statements describing pressure-filled mental states and use of pressure-relief strategies were used in the Trying To Quit smoking questionnaire (TTQ).

5.2 THE TRYING TO QUIT SMOKING (TTQ) INSTRUMENT (STUDIES III-IV)

The original TTQ is a 19 item questionnaire. Two items describing the process of trying to quit smoking were excluded as a result of the psychometric analyses of the instrument with exploratory analysis. Three factors accounted for 85 % of the total variance in responses. After revision, 3 items were excluded and the total variance increased to 96 %. The final model has 3 factors and 14 items (Table 5). Factor 1, *Developing pressure-filled mental states* includes perceptions of being criticized by family, friends and health care providers, constantly thinking about quitting smoking, feeling worthless. Factor 2, *Use of destructive pressure-relief strategies*, includes statements about reasons for not proceeding to an action phase, such as being too old, feeling that one's health will not improve, and thinking it is enough just cut down on number of cigarettes. Factor 3, *Ambivalent thoughts*, include feelings of lack of support, not wanting information about the progression of the disease, being afraid of physical reactions to abstinence and feelings obliged to quit but also accepting information about new methods of smoking cessation. Women seem to have significantly higher scores on pressure-filled mental states than men.

5.2.1 The association between TTQ scores and quit attempt, reduction in number of cigarettes or complete abstinence

An increase in the total score on the 19-item TTQ was associated with a 10 % (OR 0.90, 95 % CI 0.83-0.98) lower probability of making a quit attempt during a 3-month period. This association was still significant after adjustment for gender, education, cigarette dependence scale score and smoking cessation counselling (OR 0.89, 95 % CI 0.80-0.98). There was no significant association in between TTQ score and reduction in the number of cigarettes smoked or complete abstinence. Total score on the revised 14-item TTQ was negatively associated with quit attempts, albeit not significantly. In subgroup analyses of people with COPD ready to try to quit smoking at baseline, an increase in the score on the pressure-filled mental states was associated with 22 % (OR 0.78, 95% CI 0.66-0.94) lower probability of making a quit attempt during the 3 months follow up. On the other hand, among people with COPD not ready to try to quit smoking an increase in the scores of pressure-filled mental states subscale was associated with increased probability of reducing the number of cigarettes per day during the 3 months between baseline and follow up. An increase in the score on the ambivalent thoughts subscale was associated with decreased probability of all three outcomes among people not ready to try to quit smoking but this result was not significant. Total TTQ score did not predict the transition from "not ready to quit" at baseline to "ready to try to quit" 3 months later. Scores on the ambivalent thoughts sub-scale were negatively associated with this transition (OR 0.78, 95 % CI 0.54-1.13), albeit not significantly.

Table 5. Items and factor pattern after varimax rotation in exploratory factor analysis (n = 63)

Item and factors	Factor loading	U*	KMO†
Factor 1. Developing pressure-filled mental states			
I feel criticized for not being able to quit smoking	0.42	0.77	0.63
I criticize myself for not being able to quit	0.72	0.48	0.73
I constantly think about quitting smoking	0.72	0.39	0.66
I perceive it as a failure that I am not able to quit smoking	0.65	0.57	0.72
I do not want to show that I smoke	0.55	0.64	0.52
Factor 2. Use of destructive pressure-relief strategies			
It is unnecessary to quit because my health will not improve	0.66	0.52	0.68
It is unnecessary to quit because I am too old	0.77	0.39	0.54
It is unnecessary to quit because decreasing the number of cigarettes is sufficient	0.78	0.39	0.52
I do <i>not</i> feel that to quitting smoking is meaningful ^a	0.48	0.62	0.51
Factor 3. Ambivalent thoughts			
I do not get support and encouragement when I try to quit smoking	0.40	0.76	0.39
I am worried about the physical reactions might have if I quit smoking	0.65	0.58	0.50
I feel that I must quit smoking	0.44	0.58	0.75
I am keen to try new methods and aids for smoking cessation ^a	-0.47	0.62	0.70
I do not want information about the progression of COPD	-0.41	0.82	0.46

*Uniqueness

†KMO, Kaiser-Meyer-Olkin coefficient, measure of sampling adequacy

^a reversed item in the analyses

6 DISCUSSION

The work presented in this thesis provides information about the type of care patients with COPD receive in primary health care services from nurses. It sheds light on the feelings and thoughts of patients with COPD who are in the process of trying to quit smoking. Finally, it presents a brief reliable new instrument useful to professionals working to support patients with COPD quit smoking. This instrument, the TTQ measures factors that influence quit attempts among patients with COPD. It can be used by health care providers to identify the difficulties the smokers are facing in their efforts to try to quit smoking. This improved understanding of patients' difficulties can help professionals individualize counselling for such patients. Furthermore, patients' awareness of their own difficulties - such as pressure-filled mental states, use of pressure-relief strategies and ambivalent thoughts - may facilitate their efforts to quit.

6.1 MAIN FINDINGS

The type of care that patients with COPD received depended on the nurse the patient met (Study I). Nurses perceived the care of patients with COPD in 4 different ways, and each perception was related to whether the nurses focused more on tasks or individuals when carrying out their work. Task-oriented nurses concentrated more on performing examinations in accordance with doctors' instructions than on patients' wishes. In contrast, the individual-oriented nurses usually took the patient and his or her problems as their starting point and focused on the patients' needs. We also found that many nurses felt frustrated and powerless in their encounters with patients who had COPD and continued to smoke. Furthermore, smokers with COPD could lose hope, become resigned to their situation and not make further attempts to quit smoking. This negative outcome was often the result of developing pressure-filled mental states and using destructive pressure-relief strategies (Study II). On the other hand, if the smokers used constructive strategies they continued to try to quit or even succeed in quitting. To measure these mental states and strategies we used the theoretical model from Study II to develop the TTQ. This brief instrument identifies and measures the difficulties patients with COPD deal with when they try to quit smoking. The TTQ instrument reliably identifies factors such as high degree of pressure-filled mental states, use of destructive pressure-relief strategies and feelings of ambivalent thoughts among patients with COPD (Study III). The TTQ was reliable and useful for predicting factors that have a negative impact on attempts to quit smoking among patients with COPD and it was useful in guiding professionals in supporting quit attempts among these patients (studies III and IV).

6.2 NURSES' PERCEPTIONS OF THE CARE OF PATIENTS WITH COPD

In Sweden, most people with chronic diseases like COPD are treated at PHCCs, and many PHCC across Sweden have organized the treatment of COPD [9]. During the period Study I was conducted, more than half of PHCCs in Mid Sweden had a specialist nurse who was responsible for organizing the treatment of patients with respiratory diseases [12]. Study I found that most nurses working at PHCCs and caring for patients with COPD tried to create

good relationships with the patients. They used dialogue and a variety of communication aids in their encounters with the patient and employed an individual-oriented perspective. On the other hand, there were also nurses who focused more on the patient as an object of an encounter than as an individual with whom they should develop a relationship; i.e., who had a task-oriented perspective.

Nurses with an individual-oriented perspective described the care of patients with COPD from a patient-centered or person-centered approach. This means that treatment was planned and carried out in dialogue with the patients, and the patients were involved in decisions about their own care. In recent years, awareness of the importance of involving patients in their own care and of person-centered nursing has grown [105]. Person-centered care includes treating people as individuals, respecting their right as people, and building mutual trust and understanding so therapeutic relationships are built [105]. Person-centered care is also consistent with the individual-oriented perspective found in our study.

Nurses who had a task-oriented perspective did not place the patient in focus to the same extent as the nurses who had an individual-oriented perspective, and they did not describe the patients as taking part in their own treatment. Such nurses also saw patients more as passive objects than as active agents in their own treatment. This view of patients as passive objects may be influenced by an earlier view of care based on a biomedical model, in which disease is defined as a biophysical malfunction, the goal of the treatment is to correct the malfunction to cure the disease, and the nurses' role is to act as doctors' assistants [131]. The problem with this model is that nurses are often in complex situations with non-adherent patients [131]. Furthermore, using a task-oriented perspective in the care of patients with COPD may lead to more dependence on routines and rules than on the patient's individual wishes [132]. Researchers have also reported that if nurses do not listen to the patient's wishes, patients can feel guilt and irritation [133]. Our study showed that nurses might adopt a task-oriented perspective because of limited experience and knowledge, not being able to set aside an appropriate amount of time for patient visits, and/or having no support from management and colleagues. At least one other study has had similar findings [129].

It is important to make it possible for nurses in primary health care to have enough time for the encounter with their patient and enough time to establish a personal relationship and individualize the standard templates for care [134, 135]. In individualized care, nurses try to activate patients' own resources by offering suggestions and options to help them to deal with the disease [105]. The purpose of using educational aids was to increase the patients' understanding of the disease and help the patients manage the disease in their daily lives.

Motivational interviewing was developed to increase the probability that health care providers would reach people's wishes and thoughts. The focus of motivational interviewing is collaborating to strengthening a person's own commitment to change, and the technique places particular emphasis on ambivalence about change [136]. Motivational interviewing can be a technique to use in an individual-oriented approach.

Nurses with a task-oriented perspective probably do not use a patient-centered approach to the same extent as individual-oriented nurses. In Study I we compared the findings with a patient-centered approach [137]. When nurses feel fearful, upset, and worried about the consequences of a patient's long-term tobacco use, there is a risk that they will use one-way communication. For instance, they might just tell the patient to quit smoking without exploring the patient's thoughts and perceptions. Now they can use the TTQ in such situations to increase the patient's own awareness of feelings and thoughts about smoking cessation.

6.3 THE PROCESS OF TRYING TO QUIT SMOKING FROM THE PERSPECTIVE OF PATIENTS WITH COPD

The most common reasons for smokers to quit smoking are concerns about the health consequences of their smoking. Secondary motivations include concerns such as being a better role model for children and others, pressure from family members, and the high cost of cigarettes [138]. Most people diagnosed with COPD are aware of the importance of quitting smoking [17, 23, 69]. Still, more than 30 % of those diagnosed with COPD continue to smoke [49]. This underscores the complexity of the difficulties smokers with COPD may face in smoking cessation. In our studies, we found that factors like protracted planning; failed quit attempts; and lack of support and negative attitudes toward their smoking from family, friends, and health care providers can influence what kind of decision patients make about smoking. Patients who are hopeful, they will succeed in making a decision to quit immediately or to try in the near future. On the other hand, patients who do not feel that it is meaningful to try to quit smoking could decide to wait or even avoid attempting to quit. A review of several studies on smoking cessation shows that number of past quit attempts and the measures of motivation to stop are highly predictive of quit attempts [139]. This is important information that can help health care providers better understand how to continue to motivate their patients in the best possible way.

Most of participants interviewed in Study II were in the process of trying to quit smoking when they were diagnosed with COPD. But there were also patients who had decided to wait to try or who had just decided to continue to smoke. The trying process could consist either of planning to quit or of actively trying to quit.

Patients in the process of trying to quit could develop pressure-filled mental states. These states could be burdensome and lead to unsuccessful quit attempts or even to giving up on making any further attempts to quit. Exposure to smoking cues such as living with smokers could derail quit attempts, as could severe withdrawal symptoms [64].

Patients used a variety of strategies to relieve pressure-filled mental states. These strategies can also be compared with different coping strategies. Studies show that people with COPD use problem-, emotion-, and avoidance-focused coping strategies [39, 41]. Problem-focused strategies aim to solve problems or alter the source of the stress. They reflect an active and positive attitude towards the problem. Some people use emotion-focused strategies to try to reduce or manage the emotional distress associated with the problem. These are more passive

strategies [39, 41]. Avoidance-focused strategies are characterized by the use of minimal effort to avoid stressful situations and by the tendency to reiterate behaviors and leave daily life unchanged [140]. Those who use constructive pressure relief strategies such as the ones found in our study seem to be more problem-focused. They try to find new methods of quitting and the support they need to succeed in quitting. Both feelings of pressure-filled mental states and use of destructive pressure-relief strategies can be compared to or be part of emotion- and avoidance- focused coping strategies. Pressure-relief strategies such as hiding smoking and avoiding frightening information can decrease emotional distress. Blaming others for their own lack of success in quitting can be part of avoidance- focused strategies.

We found that women had statistical higher scores than men on measures of pressure-filled mental states, use of destructive strategies, and ambivalent thoughts, which may indicate that women use avoidance-focused strategies to a larger extent than men. Previous research has also reported that avoidance-focused strategies are more common among women than men [41].

Smokers sometimes believe that the damage has already been done and it is too late to quit [141, 142]. This can be especially true of smokers with COPD. Feeling criticized by others can be sufficient motivation to quit and maintain abstinence [65], but it can also be a stressor that hinders people from quitting. Therefore, the reasons for failing to quit smoking are complex.

If patients used constructive pressure-relief strategies, they continued to try to quit smoking or even just quit. Study III used statements made by smokers and former smokers with COPD to develop the TTQ, which can be used to identify factors that influence quit attempts in individual patients. Psychometric analyses found that the TTQ seems to provide a reliable measure of these factors. Study IV measured the predictive ability of the TTQ. The results indicated that high total TTQ scores were associated with a lower probability of successes in quitting, fewer quit attempts, and decreasing the number of cigarettes smoked. It seems, though, that people ready to try to quit smoking and who had high scores in the subscale that measured pressure-filled mental states make fewer quit attempts. On the other hand, patients not ready to quit make fewer quit attempts if they score high on the subscale that measures ambivalent thoughts.

6.4 TRYING TO QUIT SMOKING (TTQ) INSTRUMENT

There are several questionnaires for measuring different aspects of smoking, including nicotine and cigarette dependence, withdrawal symptoms, mood, and self-efficacy in smoking cessation [90, 93-95, 97, 99]. None of these measures the specific feelings smokers with COPD deal with. To fill this gap, we constructed the TTQ. We transformed quotations from interviews with COPD patients into statements that refer to factors found to be relevant to pressure-filled mental states and constructive and destructive pressure-relief strategies identified in Study III. Following psychometric analyses, the items that did not fit in the factor analysis were subsequently removed from the final model and from the TTQ.

6.5 FACTORS THAT INFLUENCED QUIT ATTEMPTS

We found that people ready to try to quit smoking but who score high on the subscale that measures pressure-filled mental states make fewer quit attempts. This is important information for health care providers. It means that at least some people in the process of try to quit smoking need support in releasing pressure-filled mental states so they do not give up on making further quit attempts and continue to smoke. On the other hand, in people not ready to quit smoking, a high score on the subscale that measures ambivalent thoughts was associated with a decrease in all three outcomes (quit attempts, 50 % reduction in number of cigarettes smoked per day, and complete abstinence). Future work should explore strategies for helping those who are not ready to quit resolve their ambivalent thoughts.

None of the patients with COPD interviewed in connection with this thesis project asked for support from health care providers in smoking cessation. This means that health care providers need to be more proactive in supporting people with COPD in smoking cessation. The TTQ can be a help in identifying those who need more support and can help tailor the support to the individuals' specific needs.

6.6 METHODOLOGICAL CONSIDERATIONS

A key strength of this thesis was its mixed method approach [143]. The two qualitative studies (I and II) provided a deeper understanding of nurses' perceptions of the care in patients with COPD and the patients' perspectives of the difficulties they face when they try to quit smoking. One of the results of Study I was the finding that nurses felt frustrated when patients with COPD continued to smoke. These results informed the quantitative studies (III and IV), including the construction of the TTQ and the testing of its psychometric properties and predictive abilities.

The qualitative studies (studies I and II)

The qualitative phenomenographic approach [114] was chosen for analyzing the transcribed interviews about the nurses' perception about the care of patients with COPD (Study I). The phenomenographic approach allowed the researchers to discern and describe the phenomenon in various ways.

GTM was used to obtain a deeper understanding of the difficulties some patients with COPD have when trying to quit smoking. GTM seeks to generate an understanding of concepts from a bottom-up analysis of textual data [110] in this thesis the theoretical model "The process of trying to quit smoking in patients with COPD". The researchers regarded the material collected from the interviews in Study II as rich, and the participants spoke openly about their experiences.

The researchers used the four criteria of credibility, dependability, conformability, and transferability to develop trustworthiness during the research process [144, 145].

Credibility involves confidence in how well data and interpretations of them address to the intended focus [145] and whether the participants will recognize the described experiences and concepts as their own [144, 145]. Twenty expert nurses responsible for the care of patients with respiratory diseases were interviewed. They had various experiences as expert nurses caring for this group of patients and could therefore describe different aspects of care. The findings were presented to a network of nurses responsible for patients with respiratory diseases in primary health care (some of them had participated in the study). They could all recognize themselves in the four perceptions of the care of patients with COPD.

The GTM approach was used to collect data in Study II through interviews with patients with COPD; all provided diverse and comprehensive data. The final theoretical model were also validated by four smokers with COPD who had not been interviewed in the study, which is a common procedure in GTM [146]. They were asked four specific questions covering the model and the relevance of the findings. As a result of their responses, some minor revisions were made. The smokers did not make any comments that contradicted the findings, which were therefore regarded as consistent and clinically relevant. Discussions about concepts and categories were also held at several academic seminars with researchers and doctoral students.

Dependability refers to the consistency and stability of evidence [144] data that are stable over time. In both Study I and Study II, researchers asked open-ended questions followed by individually adapted follow-up questions. In Study I the nurses were asked to begin with a description of the care of patients with asthma and then to describe the care of patients with COPD. This was a deliberate strategy to ensure that all nurses meant the same group of patients as having either asthma or COPD. The transcribed interviews about asthma were not analyzed. All interviews were done by the first author and started with the same questions (studies I and II) [145]. In Study II, we ensured the rigor (quality in data) of the study by thoroughly following the methodology and immediately transcribing the interviews and writing memos throughout the whole process of analysis.

Conformability is the degree to which the results are derived from data from the participants and the context of the study rather than from the researcher's bias [144]. Prior understanding and pre-existing knowledge can sometimes aid concrete understanding. However, they may also constitute a bias and negatively influence the analysis [147]. It is important that the authors' preconceptions and experiences not influence data collection and data analysis in an unintended way [148].

The first author worked for several years at PHCCs as a specialist nurse caring for patients with respiratory diseases. She also provided smoking cessation counseling. It can be argued that it is impossible for a researcher who has spent time working in the profession he or she is studying to have an unbiased opinion of matters related to that profession. This risk of bias must be balanced by the analytical work and quotes from interviews should be used to strengthen the data [145]. As a researcher familiar with PHCCs and the field of smoking cessation, it was important to develop strategies to avoid unduly influencing the data. This

risk was also balanced by the others in the research group who also read through the data. As the concepts emerged, frequent meetings were held with supervisors who became well-acquainted with the material, which included manuscripts, tapes, and memos of the interviews made during the collection and analysis. The research group exchanged ideas for making possible connections between concepts and underlying issues, as also stated by Polit and Beck (2012) [145].

Transferability refers to the generalizability of the data whether conclusions made on the basis of the data can be transferred to other settings or groups [145]. The theoretical model is grounded in empirical data, and the substantive categories are applicable to the context from which they emerged; i.e., patients with COPD. However, these theories might have relevance for similar contexts with other patients, but must be tried in each new context before fit can be assured. The substantive theories were also used in the construction of the TTQ instrument.

The quantitative studies

Reliability and validity are the two most important criteria for evaluating quantitative instruments. An instrument has to be reliable (measure target attributes consistently). If it contains too much error in reliability, it cannot be valid (measure the trait it is supposed to measure without systematic distortion). Furthermore, instruments can be reliable without being valid. Scales that involve summing item scores are usually evaluated for their consistency. In nursing research, the most widely used test of reliability is a test of internal consistency [145]. Cronbach's alpha coefficient was used to evaluate the internal consistency of the TTQ. The normal range of values is from 0.00 to 1.00. Higher values reflect a higher internal consistency. The TTQ had a value of 0.71, which is considered satisfactory.

Validity can be sometimes difficult to establish, especially when an instrument is new and no gold standard (generally accepted reference to which it can be compared) is available. The face validity (the extent to which a measuring instrument looks as though it is measuring what it is meant to measure) of the TTQ was measured by specialist nurses in pulmonary disease and by smokers with COPD. They were asked to judge the comprehensibility of each item, the relevance of questions and the response alternatives, and whether the TTQ appeared to measure the target variables. The most important test of validity, however, was the analysis of the instrument's ability to predict future smoking cessation outcomes, which turned out to be satisfactory.

Exploratory factor analyses (EFA) was used to measure the psychometric properties of the TTQ and to reduce the number of items that explain each factor [149]. The choice to use EFA can be debated. Usually this method is used when the researcher has no expectations of the number or nature of the variables, and as the title suggests, this kind of analysis is exploratory in nature [149]. The theoretical model of the process of trying to quit smoking was new, and EFA allowed us to explore the main dimensions of the process from the using a set of latent constructs represented by a number of items. The final model on which the TTQ was based

included 3 factors and 14 items. The excluded items had both multiple loadings and high uniqueness.

One of the strengths of the study is that it was performed in a natural clinical setting (PHCCs). Another is that the TTQ was easy for the participating nurses to administer and for patients to complete. The participants (patients diagnosed with COPD) completed the TTQ in dialogue with the nurse, which probably ensured that there were no missing responses to items. A limitation was the small sample size, which makes it difficult to draw conclusions about the predictive ability of the sub-dimensions of the instrument.

7 CLINICAL IMPLICATIONS

The findings described in this thesis highlight some challenges health care professionals face in attempting to improve smoking cessation support for patients with COPD. Nursing programs and continuing education for health professionals should pay special attention to support and guidance of new and inexperienced and task-oriented nurses. It is important to identify difficulties that each patient with COPD faces when trying to quit smoking in order to avoid the risk that the patient will lose hope and give up his or her attempts to quit. Two difficulties deserve special attention: pressure-filled mental states and/or ambivalent thoughts. These two mental processes were negatively correlated with attempts to quit. They are conceptually different from and not included in the definition of tobacco dependence, and information about these two mental processes can be useful when planning for smoking cessation programs. By preventing patients from resigning themselves to continued smoking, counseling tailored to patients' needs may help reduce feelings of frustration, both among health care providers and among patients. The TTQ developed in the course of this doctoral project can raise awareness of factors influencing the thoughts and beliefs of smokers who have COPD. This information can be especially useful in encounters with smokers who have COPD and are unwilling or have difficulties to make a quit attempt.

8 CONCLUSIONS

- Continued education for nurses should focus on support and guidance to inexperienced and task-oriented nurses.
- Nurses should be aware that patients with COPD experience pressure-filled mental states and sometimes use destructive strategies when trying to quit smoking. This awareness should be reflected in the methods the nurses choose to use in counseling (e.g. motivational interviewing).
- The new assessment instrument "Trying to Quit smoking" (TTQ) can be useful in predicting cessation outcomes, such as attempts to quit smoking among patients with COPD. The TTQ can also identify specific obstacles to successfully quitting smoking in such patients and facilitate rational treatment choices.
- The brief TTQ instrument can identify specific obstacles to successfully quitting smoking in COPD patients – both those who are ready and those who are not ready to start the process. Nurses and other health care providers can therefore use the instrument to support rational choices when counseling patients with COPD who smoke.
- There are several questionnaires for measuring different factors relevant to smoking cessation, such as nicotine and cigarette dependence, withdrawal symptoms, mood, and self-efficacy. None of these measure the specific feelings smokers with COPD deal with.

9 FUTURE PERSPECTIVES

The TTQ needs to be studied in a larger sample of patients with COPD. It would also be interesting to use the TTQ to study patients who smoke with other chronic diseases. Finally, nurses' perception of using the TTQ should also be investigated.

10 SAMMANFATTNING PÅ SVENSKA/SUMMARY IN SWEDISH

10.1 BAKGRUND

Antalet patienter med kroniskt obstruktiv lungsjukdom (KOL) ökar i hela världen [2]. De flesta patienter med KOL i Sverige vårdas inom primärvården [8, 9]. KOL är en progressiv kronisk sjukdom som kan leda till känslor av skuld, och stigmatisering på grund av upplevelsen av att ha orsakat sjukdomen själv, oftast genom tobaksrökning [20, 22, 23]. Ungefär hälften av patienterna med KOL lider av depression och ångest [24, 61]. En viktig del i omvårdnaden är att stödja och hjälpa patienter med KOL att sluta röka. Sjuksköterskor spelar en viktig roll i att stödja patienter till en bättre livskvalitet [4]. För att kunna ge kvalificerat rådgivande samtal i rökavvänjning behövs kunskap om och förståelse för patientens erfarenheter [86]. I socialstyrelsen nationella riktlinjer för vård av patienter med astma och KOL, finns kriterier framtagna för en godkänd astma/KOL mottagning som innehåller strukturerad patientutbildning utifrån patientens behov och egenvårdsmål [1, 12, 13].

Tobaksrökning är den största bidragande orsaken till utveckling av KOL, och rökstopp är den enda behandling som kan minska progressionen av sjukdomen. Det är därför viktigt att diagnos ställs tidigt och att patienter erbjuds rökavvänjningsstöd. Hälften av alla patienter med KOL fortsätter att röka efter diagnos [69]. Det är väl känt att många misslyckade rökstoppsförsök kan leda till lågt självförtroende, skam och känsla av att vara värdelös [20, 65]. När det gäller tobaksavvänjning stöd har det visat sig att kvalificerade rådgivande samtal av en utbildad rökavvänjare är mer effektivt än enbart ett kort råd om rökstopp [88]. För att stödja patienter att sluta röka är det även viktigt att identifiera faktorer som negativt påverkar försök att sluta röka. Det finns ett flertal instrument framtagna som bidrar till att identifiera olika aspekter av tobaksberoende. För att mäta nikotinberoende finns Fagerströms beroendskala [91]. Instrumentet är vanligt förekommande men har sina begränsningar. På senare år har nya aspekter på beroende framkommit som t.ex. i formuläret Cigarette dependence scale (CDS). CDS innehåller frågor om tvång att röka, röksug, tappad kontroll, avstånd från andra aktiviteter till förmån för rökning och fortsatt rökning trots skadliga effekter [94]. Det finns även ett flertal andra frågeformulär som mäter ytterligare aspekter om rökning och rökstopp [97, 99, 100]. Inget av dessa frågeformulär mäter emellertid de svårigheter som patienter med KOL upplever när de försöker sluta röka. Det finns därför ett behov av studier som undersöker detta. Det behövs också ett verktyg som personalen kan använda som stöd vid samtal om rökavvänjning med patienter med KOL.

Syftet med denna avhandling är att beskriva omvårdnaden av patienter med KOL i primärvården, och att beskriva faktorer som påverkar rökande patienter med KOL i deras rökstoppsförsök. Ett ytterligare syfte är att utveckla ett reliabelt och valit instrument som mäter de svårigheter som rökare med KOL upplever när de försöker sluta röka, och som kan användas i dialog med patienterna för att identifiera dessa svårigheter.

10.2 MATERIAL OCH METOD

I studie I intervjuades 20 distriktssköterskor och sjuksköterskor som arbetade inom primärvården under perioden februari - maj 2003. Samtliga hade ett utökat ansvar för patienter med lungsjukdomar och ombads beskriva vården av patienter med astma och KOL. Fenomenografisk ansats användes vid analys av data för att beskriva sjuksköterskors uppfattningar om vården av patienter med KOL.

I studie II intervjuades 14 patienter med KOL under åren 2005 - 2007 för att undersöka deras svårigheter i försöken att sluta röka. Grundad Teori användes vid urval av deltagare samt vid kodning och analys av de semistrukturerade intervjuerna. Ytterligare 4 intervjuer genomfördes för att validera den teoretiska modell som blev slutresultatet.

Studie III genomfördes inom primärvården i Stockholms läns landsting under åren 2011-2013. Ett nätverk av sjuksköterskor med specialistkunskaper inom lungsjukdomar som arbetade med mottagning för patienter med KOL erbjöds att delta i studien. Av de tillfrågade sjuksköterskorna var 31 villiga att delta. De ombads att rekrytera 5 patienter var. Patienterna skulle vara rökare, ha diagnosen KOL samt ha förmågan att svara på ett frågeformulär på svenska. Totalt rekryterades 102 patienter vilka besvarade bedömningsinstrumentet ”Trying to Quit smoking” (TTQ). TTQ utvecklades utifrån resultatet i studie II dvs. utifrån den teoretiska modellen i syfte att kunna mäta faktorer som påverkar ett lyckat rökstoppsförsök. Sextiotre av de 102 patienterna visade sig vara i processen att försöka sluta röka och inkluderades i den psykometriska analysen. Den interna validiteten av bedömningsinstrumentet testades av både sjuksköterskor med utbildning inom lungsjukdomar och av rökande patienter med diagnosen KOL. För att undersöka faktorstrukturen och mäta reliabilitet av TTQ gjordes en exploratorisk faktoranalys (EFA).

Deltagarna i studie IV var desamma som i studie III men ytterligare 7 patienter rekryterades, dvs. totalt 109 rökande patienter med KOL. Efter att patienterna besvarat TTQ i dialog med sjuksköterskan, svarade de också på frågor om cigarettberoende, riskbruk av alkohol samt ångest och depression (HAD). Samtliga patienter fick ett informationsblad med tips om rökstopp och rökavvänjningsstöd enligt lokal rutin. Patienterna följdes sedan upp efter 3 månader med registrering av givna rökavvänjningsinsatser, rökvanor, antal rökstoppsförsök och varaktig rökfrihet (7 dagars punktprevalens). Analyser gjordes med logistisk regression för att undersöka sambandet mellan poäng i TTQ och utfallsvariabler som rökstoppsförsök (som varat i 24 timmar), minskning av antalet cigaretter med 50 % och rökfrihet vid mättillfället (minst 7 dagar).

10.3 RESULTAT

De flesta patienter som sjuksköterskorna mötte inom primärvården var äldre med moderat till svår form av KOL (studie I). Vården beskrevs utifrån två perspektiv, uppgiftsorienterad eller individorienterad. Inom dessa två perspektiv beskrevs vården som att: a) skapa engagemang och delaktighet genom goda relationer, b) tillföra kunskap genom att använda olika verktyg och hjälpmedel, c) samarbeta med eller hänvisa till andra vårdgivare, d) utföra

undersökningar och behandlingar på ordination av t.ex. läkaren. Sjuksköterskorna upplevde ibland frustration och maktlöshet i mötet med patienter som fortsatte att röka efter att de fått diagnosen KOL.

Resultatet i studie II beskriver en teoretisk modell av processen "Patienter med KOL som försöker sluta röka". Patienter som bestämmer sig för att försöka sluta röka kan utveckla pressliknande tillstånd som att känna sig kritiserad av vänner, anhörig, vårdpersonal men också av sig själv etc. Modellen beskriver faktorer som är relaterade till beslut om rökningen och användning av destruktiva alternativt konstruktiva strategier för att lösa känsla av press. Om patienten använder sig av konstruktiva strategier så leder det till att de fortsätter att försöka att sluta röka eller lyckas med sitt rökstoppsförsök. Om de däremot använder sig av destruktiva strategier så kan det leda till att de resignerar och inte fortsätter att försöka sluta röka.

Den teoretiska modellen användes för att utveckla ett bedömningsinstrument "Trying to quit smoking" (TTQ) med 19 frågor som är tänkt att mäta faktorer som försvårar ett lyckat rökstoppsförsök (studie III). Psykometriska analyser med exploratorisk faktoranalys (EFA) visar att den interna reliabiliteten var 0.71 mätt med Cronbach's alpha. I den roterade analysen av TTQ minskades antalet frågor till 14 vilka grupperades i tre faktorer med en total varians på 96 %. Detta ansågs tillfredsställande. De tre faktorerna benämns som, utveckling av presstillstånd, användning av destruktiva presslindrande strategier samt ambivalenta tankar. Kvinnor upplevde signifikant mer presstillstånd (dvs. hade högre poäng) än män.

I studie IV undersöktes den predicerande förmågan av TTQ och sambandet med tre utfallsmått, rökstoppsförsök, minskning av antalet cigaretter till hälften och varaktig rökfrihet. Resultatet visade att en ökning i total poäng av TTQ (19 frågor) var associerat med 10 % lägre sannolikhet att göra ett rökstoppsförsök (OR 0.90, 95 % CI 0.83-0.98). Med det kortare TTQ instrumentet (14 frågor) fanns inget signifikant samband mellan poäng och rökstoppsförsök, minskning i antal cigaretter eller varaktig rökfrihet. Subgruppsanalyser av de patienter som var redo att försöka sluta röka, visade ett signifikant samband mellan ökning i poäng av presstillstånd och 22 % lägre sannolikhet att göra ett rökstoppsförsök (OR 0.78, 95 % CI 0.66-0.94). Bland de som inte var redo att försöka sluta röka fanns en tendens (icke signifikant) av ökning i poäng av ambivalenta tankar och en mindre sannolikhet att göra ett rökstoppsförsök, minska antalet cigaretter eller varaktig rökfrihet. Det fanns också ett signifikant samband i gruppen av patienter inte var redo att försöka sluta röka mellan ökning av presstillstånd och sannolikheten att minska antalet cigaretter.

10.4 SLUTSATS

Denna avhandling beskriver både distriktssköterskors/sjuksköterskors uppfattningar om vården av patienter med KOL och patienters upplevelse av sin egen rökning och försök att sluta röka. Den vård som patienter med KOL får beror på om de möter en uppgifts- eller individorienterad sjuksköterska. Uppgiftsorienterade sjuksköterskor kan behöva stöd i att individualisera vården för personer med kroniska sjukdomar. Vårdpersonalens attityder samt

patienternas egen motivation och tro på sin förmåga kan ha en påverkan på vilket beslut patienten tar om sin egen rökning. Det finns ett flertal frågeformulär som mäter olika aspekter av rökning och cigarettberoende men inga av dessa mäter de faktorer som påverkar patienter med KOL i deras rökstoppsförsök. TTQ kan därför vara ett viktigt instrument för att medvetandegöra både patienten och vårdpersonalen om förekommande negativa faktorer som kan påverka rökstoppsförsök. Medvetenhet om faktorerna kan hjälpa sjuksköterskor att individualisera stödet till rökande patienter med KOL.

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