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Communication in Smoking Cessation and Self-management

A Study at Nurse-led COPD-clinics in Primary Health Care

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ABSTRACT

The general **aim** of this thesis was to investigate behavioral change communication at nurse-led chronic obstructive pulmonary disease (COPD) clinics in primary health care, focusing on communication in self-management and smoking cessation for patients with COPD.

Designs: Observational, prospective observational and experimental designs were used.

Methods: To explore and describe the structure and content of self-management education and smoking cessation communication, consultations between patients (n=30) and nurses (n=7) were videotaped and analyzed with three instruments: Consulting Map (CM), the Motivational Interviewing Treatment Integrity (MITI) scale and the Client Language Assessment in Motivational Interviewing (CLAMI). To examine the effects of structured self-management education, patients with COPD (n=52) were randomized in an intervention and a control group. Patients' quality of life (QoL), knowledge about COPD and smoking cessation were examined with a questionnaire on knowledge about COPD and smoking habits and with St. George's Respiratory Questionnaire, addressing QoL.

Results: The findings from the videotaped consultations showed that communication about the reasons for consultation mainly concerned medical and physical problems and (to a certain extent) patients´ perceptions. Two consultations ended with shared understanding, but none of the patients received an individual treatment-plan. In the smoking cessation communication the nurses did only to a small extent evoke patients' reasons for change, fostered collaboration and supported patients' autonomy. The nurses provided a lot of information (42%), asked closed (21%) rather than open questions (3%), made simpler (14%) rather than complex (2%) reflections and used MI non-adherent (16%) rather than MI-adherent (5%) behavior. Most of the patients' utterances in the communication were neutral either toward or away from smoking cessation (59%), utterances about reason (desire, ability and need) were 40%, taking steps 1% and commitment to stop smoking 0%. The number of patients who stopped smoking, and patients' knowledge about the disease and their QoL, was increased by structured self-management education and smoking cessation in collaboration between the patient, nurse and physician and, when necessary, a physiotherapist, a dietician, an occupational therapist and/or a medical social worker.

Conclusion The communication at nurse-led COPD clinics rarely involved the patients in shared understanding and responsibility and concerned patients' fears, worries and problems only to a limited extent. The results also showed that nurses had difficulties in attaining proficiency in behavioral change communication. Structured self-management education showed positive effects on patients' perceived QoL, on the number of patients who quit smoking and on patients' knowledge about COPD.

Keywords: Chronic obstructive pulmonary disease, Client Language Assessment in Motivational Interviewing, Communication, Consulting Map, Motivational Interviewing Treatment Integrity , Nurse-led clinics, Patient education, Primary health care, Quality of life, Self-management, Smoking cessation.

LIST OF PUBLICATIONS

This thesis is based upon following publications, which are referred to in the text by their Roman numerals:

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LIST OF ABBREVIATIONS

CLAMI	Client Language Assessment in Motivational Interviewing
CM	Consulting Map
COPD	Chronic obstructive pulmonary disease
GOLD	Global Initiative for Chronic Obstructive Lung Disease
HRQoL	Health Related Quality of Life
ICC	Intra-class coefficient
MET	Motivational Enhancement Therapy
MI	Motivational Interviewing
MISC	Motivational Interviewing Skills Code
MITI	Motivational Interviewing Treatment Integrity
PEF	Peak expiratory flow
PHC	Primary Health Care
PHCC	Primary Health Care Clinic
PRO	Patient/person reported outcome
QoL	Quality of Life
SGRQ	St. George`s Respiratory Questionnaire
SHR	Self-reported health
TBC	Target Behavior Change
TTM	Transtheoretical Model of change
VAS	Visual analogue scale

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1 INTRODUCTION

Over the last three decades chronic diseases have overtaken infectious diseases among the leading causes of death in high income areas of the world. The leading causes of morbidity and mortality are attributed to life style behaviors such as physical inactivity, poor dietary habits, tobacco use, and alcohol consumption. [1-3]. It is estimated that 50% of mortality from the ten leading causes of death is attributable to life style behavior. That implies that people's care needs have changed as a consequence of an unhealthy life style, and that individuals can enhance their health by choosing health-related behaviors and avoiding unhealthy behaviors [4].

Today we know that communication is an important treatment tool to improve self-management and smoking cessation for persons with chronic diseases [5-6]. Good communication, including mutual understanding and collaboration between patient and physician, was highly effective in patient education and led to a positive influence on emotional health, symptoms resolution, functional status and pain control [7]. A later Cochrane review established that information alone is not enough to change behavior [8]. A study in cancer care showed that communication is a complex process that requires time; three years' communication training for health care professionals raised the quality of the communication and increased patients' satisfaction with the quality of care [9]. This is further supported in patient participation in education interventions, specifically tailored to individual needs, showing a positive influence on the interaction between nurse and patient, and encouraging patients to be active partners in their care [10].

Nurses will in the future work to a larger extent with patients with chronic illnesses to support their health. This will require new knowledge, new skills, new care organization and new professional roles. Patients will be best supported by a comprehensive view combining different methods to grasp and consider the complexity of their illness [11]. In that context, nurse-led clinics for patients with chronic diseases e.g. diabetes, heart failure, asthma and COPD, are faced with the challenge of how best to support these patients.

2 BACKGROUND

Supporting people in changing an unhealthy life style is in accordance with Swedish national law and guidelines, and also with WHO:s European strategy for welfare diseases. In the "Swedish Health Care Act" (1982:763) the disease prevention perspective was clearly expressed as early as 1983. The "Patient Safety Law" (2010:659 chapter 6, included in the act above) states that care as far as possible shall be designed and performed in agreement with the patient (§1) and that patients should be given individually adapted information about their state of health and available methods for care and treatment (§6). The Swedish government also has emphasized in the proposition "Reconsidered policies for public health" that health care shall in future integrate a disease prevention perspective (Prop.2007/08:110).

The World Health Organization (WHO) European region has accepted the Warsaw declaration's guidelines for a tobacco-free Europe. In that declaration it is established that smoking cessation is an evidence-based and crucial part of the work against tobacco. Each country is therefore expected to educate their health care professionals on tobacco dependence and smoking cessation methods [12]. The report "Tobacco or health in the European Union", provides recommendations for future work against tobacco and methods of limiting the effects of smoking [13].

Further, support of a healthy life style has been stressed as an important intervention in the national guidelines for asthma and COPD [14], as well as in guidelines for other chronic diseases. In the Global strategy for COPD it has been stated that there is a need to establish structured programs for COPD care, including smoking cessation, with the ambition of individualizing care and treatment for patients and assessing the benefit of each approach at each stage of the illness [15].

2.1 SMOKING CESSATION

The most crucial aspect for smokers with COPD is to quit smoking. However, it is difficult to help patients with COPD to stop smoking because they are particularly addicted to nicotine, as compared to smokers who do not have COPD [16-17]. It should be acknowledged that, for people with COPD, the combination of advanced age, duration of smoking and degree of addiction will make it especially difficult to quit smoking [18-19]. However, it has been shown that COPD patients with more severe respiratory symptoms were amenable to counseling and maybe more motivated to quit smoking [20]. A review of the evidence for smoking cessation interventions in people with COPD indicated that the most effective strategy was the use of nicotine replacement therapy (NRT) together with intensive behavioral support to prevent relapse [19]. It has also been shown in two meta-analyses that counseling and medication are most efficient when used together [21-22]. Group counseling for smoking cessation has shown to be as effective as intensive individual counseling [23].

2.2 SELF-MANAGEMENT

Self-management education is a crucial component in the care of chronic disease and for patients' ability to cope with illness [24]. In self-management education, patients should be considered as active partners in their health care. They are responsible for managing their own situation, and for living as emotionally satisfying lives as possible, in spite of ill health [25-26]. Self-management support for patients with chronic diseases is defined by the North American Development Agency as:

"*the systematic provision of education and supportive interventions to increase patients' skills and confidence in managing their health problems, goal setting, and problem solving support*" [27] (p 2)

Self-management is not only about what patients do in order to live with their disease, but also about what professionals do to support patients. Self-management support should be delivered in the form of seven primary components: 1) providing information and support; 2) teaching people disease-specific skills; 3) encouraging the choice of healthy behavior; 4) training in problem solving, 5) assisting with the emotional impact

of having the condition; 6) providing regular and sustained follow up; and 7) encouraging participation in active management of the condition.[27].

2.3 QUALITY OF LIFE

The goals of treatment and self-management at nurse-led COPD clinics are to improve functioning in daily life and to improve well-being. Quality of life (QoL) is one outcome of improved self-management and smoking cessation. Measuring QoL is therefore of particular relevance for patients with chronic diseases. QoL-instruments are classified as generic or disease-specific. Other terms, similar to QoL, are health-related quality of life (HRQoL), patient/person reported outcome (PRO) and self-reported health (SHR). Irrespective of which term is used, interest is in patients' experience and self-reported QoL. HRQoL is the main concern for health care professionals and is used in health care to measure the effects of chronic illness, offering a better understanding of how illness interferes with a person's day-to-day life [28]. QoL is a multi-dimensional subjective concept including physical, social and psychological functioning and there are various definitions of QoL [29-32]. In conclusion, the definition concerns problems that are troublesome for the patient and how these problems interfere with activities in everyday life.

2.4 BEHAVIORAL CHANGE COMMUNICATION

Self-management education and smoking cessation require skills in behavioral change communication. It has been shown that it is difficult to change communication style from the authoritarian expert approach, in which nurses have often been trained and socialized [33], into a patient empowerment approach, based on the recognition that patients are in control of self-management decisions affecting their quality of life [34]. To reach the desired goals of behavior change it is therefore important to focus on methods that achieve these results. In behavioral change communication it is recommended to base qualified counseling on one or more patient-centered and theory-based methods or models of communication. At the core of the methods and models are asking open questions and using reflective empathetic listening, aimed at a better understanding and exploration of the patient's motivation and self-efficacy.

2.4.1 Empowerment

Empowerment as a concept was developed by Paulo Freire in the "social action" ideology of the 1960s and the "self help" perspectives of the 1970s [35] and has been central ideology in health care since the 1980´s [36]. Patient empowerment is a process where the purpose of an educational intervention is to increase one's ability to think critically and act autonomously. It results in an outcome when an enhanced sense of self-efficacy occurs as a consequence of the process. [37]. Empowerment is an outcome of communication and education in which knowledge values and power are shared [38-39], entailing continuity, patient-centeredness, mutual acknowledgement and relatedness [39]. The process occurs while the patient tells his/her history and the health care provider facilitates the understanding they both gain of the patient's situation, thus adding and or creating meaning to the patient's experiences [40-42]. Empowerment consists of three components: intrapersonal, interactional, and behavioral. The intrapersonal component treats empowerment as a

personality variable such as perceived control, self-efficacy, motivation to exert control, and perceived competence. The interactional component includes knowledge about needed resources and problem-solving skills, whereas the behavioral component refers to specific actions taken to exercise influence through participation in organizations and activities [43].

2.4.2 Motivational Interviewing

2.4.2.1 History

Motivational interviewing (MI) originated in the treatment of substance abuse in the early 1980s by William R Miller [44]. The primary theoretical grounding of MI can be found in Carl Rogers's research on non-directive counseling 1953 and in his person-centered therapy first described 1957. Rodgers developed principles of reflective listening and believed that learning is only possible when individuals have confidence in their own learning ability [45-46]. Motivational interviewing has emerged as a counseling approach for behavioral change and builds on a patient empowerment perspective by supporting self-efficacy. MI is defined as "a collaborative, person-centered form of guiding to elicit and strengthen motivation for change" [47] (p.137). It is non-judgmental, non-confrontational and non-adversarial communication. The approach attempts to increase the patient's awareness of the cause of the problem, its consequences, and risks. The main goals of MI are to establish understanding, elicit talk about change, establish commitment language and behavior change [48].

MI has been increasingly used in medicine and public health over the last 20 years [47, 49] and has been applied to populations affected by a broad range of behavioral issues, including management of alcohol, nicotine, physical activity, HIV risk behavior, diabetes, and obesity [50-52]. There are MI trainers and translations in at least 38 languages. The Motivational Interviewing Network of Trainers (MINT), established in 1995, is an international collective of trainers who have educated and trained more than 1500 MI trainers, who in turn have trained clinicians [47].

MI is also introduced widely in Swedish PHC, and county councils responsible for PHC across Sweden agree that it is important for PHC-staff to have knowledge in MI. Today at least 60% of all nurses in Swedish PHC, have been educated in MI. Managers in Swedish PHC look upon MI as a strategy to enhance the process towards increased health in the population. The national county council coordinator for risk-use and tobacco prevention has also stated that MI is a fundamental factor for success in their work towards change[53].

2.4.2.2 The features of MI

The **spirit of MI** involves ability and willingness to be close enough to a client to get a glimpse of their inner world [54]. The MI spirit is defined in terms of three characteristics: 1) Collaborative, a collaborative partnership between the client and the practitioner. 2) Evocative, evoking the client's own arguments and reasons for change. 3) Honoring clients' autonomy, including acceptance that clients can make choices that may not result in the desired health improvements. The practitioner may inform or advise, yet it is ultimately the client who decides what to do [55].

MI has **four guiding principles**: 1) *To understand and explore the patients' own motivation*; involves exploring the pros and cons of the patient's behaviors and of

change behavior, within a supportive and accepting atmosphere, in order to generate or intensify an awareness of the discrepancy between the patient's current behaviors and broader goals and values. 2) *To listen with empathy*: Empathy is seen as crucial to the provision of necessary conditions for a successful exploration of change to take place. Reflective listening is an important part of this characteristic. Empathy in MI is not only warmth, acceptance, genuineness, or client advocacy. It is also a deeper understanding of the patients' talk, in order to grasp their perspective and feelings. 3) *To empower the patients and encourage hope and optimism:* change will occur when the patient has the resources and capabilities to overcome barriers and successfully implement new ways of behaving. MI is to support self-efficacy by helping clients to believe in themselves and become confident that they can carry out the changes they have chosen. 4) *To resist the righting reflex*: Avoidance of arguing with a client about his or her need for change is regarded as critical in MI. It is proposed that direct confrontations about change will provoke reactance in clients and a tendency to exhibit greater resistance, which will further reduce the likelihood of change [55].

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Five foundational **MI skills** that are consistent with the principles and spirit of MI are: 1) *Asking open-ended questions*: open-ended questions are used to allow clients to do most of the talking in a counseling session. Open ended questions help clients gain better access to their true feelings and thoughts, so that they can better be recognized. 2) *Reflective listening*: reflective listening from practitioners helps clients to verbalize and make their meaning more explicit. This is necessary because people do not always express their thoughts clearly due to other concerns, or because they are simply not able to find the proper words to convey their experience. 3) *Affirmations*: In MI the counselor should frequently affirm the client in the form of statements of appreciation or understanding in order to encourage and support the client during the change process. 4) *Summarizing:* Summary statements are used to link and draw together the material that has been discussed, showing that the counselor has been listening. Summaries are particularly useful to collect and reinforce change talk. 5) *Eliciting change talk*: Change talk consists of statements reflecting desire, perceived ability, need, readiness, reasons or commitment to change and is important to provide the client with a way out of their ambivalence [56].

2.4.2.3 Change and sustain talk in MI

Motivated patients participate more actively in behavior change, engage more in self-disclosure and assume greater responsibility in their efforts towards change [57-58]. Change talk is a response from a motivated patient and also a central component of good MI practice. In MI, patients are encouraged to express their attitudes towards behavioral change and monitor their own progress in this regard. In smoking cessation, change talk includes recognizing the disadvantages of continuing to smoke, stating the advantages of stopping smoking and expressing the intent to change. Conversely, "sustain talk" would be a response where the patient denies the need for changes [59-60]. There is scientific support for counselors' MI-consistent language being positively associated with client change talk, and for counselors' MI-inconsistent language being positively associated with sustain talk [60-67].

2.4.2.4 Implementation of MI

Most MI training for clinicians is provided in the form of workshops lasting for 1–3 days, including an introduction to the philosophy and principles of MI, demonstration of the method, and guided practice in learning the skills [68]. Coding of practice samples is the method used for measuring MI fidelity, using audio- or videotaped

samples, with or without transcripts. As with all coding systems, a transcript should never be used on its own since the resulting loss in voice tone, inflection and pace renders an unacceptable loss of information and reliability. Clinicians' self-reported proficiency has been found to be unrelated to actual practice proficiency ratings by skilled coders [51, 69].

MI is commonly delivered to patients in one to four sessions. [70] The sessions could be described in two phases. The first ambivalent phase is when the patients are not sufficiently motivated to accomplish change. The aim of this phase is to resolve the client's ambivalence and facilitate increased intrinsic motivation to change. When the patient shows readiness to change the second phase starts. Signs of readiness from the patient could be talk or questions about change, descriptions or suggestions on how to change and/or envisioning a future when the desired changes have been made. The focus in the second phase shifts to strengthening the commitment to change and supporting the client to develop and implement a plan to achieve those changes [56].

2.4.2.5 Coding system for MI

The first process rating system was the Motivational Interviewing Skills Code, or MISC [71], which was developed in 2001 by Miller and Mount and refined in subsequent clinical trials [51, 72]. The original MISC required three coding passes through the video- or audio taped consultation, one for the Global skills rating, one for the therapist and client behavior counts, and one for relative talk time. In order to reduce time demands, a simplified MI Treatment Integrity (MITI) code was developed that focused only on therapist behaviors, one coder listening to the entire consultation for both MITI global score and behavior codes [73]. The Client language assessment in Motivational Interviewing (CLAMI) is intended for assessing client language. The entire session is coded and a code is assigned every time the client speaks. The CLAMI assesses only client language, not clinician behavior, and has been designed to be compatible with the coding systems MISC 2.0 and MITI, which focus on clinician behavior in detail. In general, the complexity of CLAMI will require a separate review of the tape, using a transcript, with clinician behavior to be evaluated on a different run through the tape [74]. Other measures for use in training or supervision, to ensure that practitioners adhere to the basic practices of MI are; Yale Adherence and Competence Scale (YACS); the Motivational Interviewing Process Code (MIPC); and the Motivational Interviewing Supervision and Training Scale (MISTS) [75].

2.4.2.6 Effectiveness of MI

In a review, the effect of MI in clinical practice has been shown to be significantly better than weak treatment (such as a written materials or waiting list controls) and also better than no treatment at all. It was at least as good as other treatments with exceptions in the case of tobacco use and miscellaneous drug use problems. However, MI is likely to produce a significant positive advantage in a shorter time. When compared to the 12-step program and cognitive behavioral therapy, MI intervention took a mean of over 100 minutes less to produced equal effects [6]. In another review of MI process research it was concluded that MI is reliably differentiated from minimal/placebo control conditions, from treatment as usual, and from other active treatment conditions such as cognitive behavioral therapy, both regarding rates of both MI-consistent and MI inconsistent therapist responses [76].

Reviews of the effects of MI on smoking cessation have shown some positive results, such as MI being effective when applied by general practitioners or by trained counselors [5], and that MI could be effective for adolescent or adult smokers [77]. When the goal of the intervention is to target a specific behavior change and if another specific program has not currently been used, it is recommended in a meta analysis that MI should be combined with problem feedback for the best outcome (Motivational Enhancement Therapy (MET)) [6]. MI used in combination with other treatments or methods appears to be more stable than MI used as a stand-alone method [6, 49, 78]. In conclusion, the best available knowledge shows that MI is as effective as other comparable communication methods for supporting people in quitting smoking [78].

2.4.3 Transtheoretical Model of health behavior change

In MI the clinicians are expected to communicate from the patients' different levels of readiness. The stages of the transtheoretical model (TTM) of health behavior change provide a logical way of thinking when judging patient readiness to behavior change in clinical practice. The idea is that the clinicians should direct the patients from an unaware attitude, through ambivalence and towards action for behavioral change. TTM is a conceptual model on how and why changes occur and how professionals reflect upon facilitating change, originally formulated to describe the process when people tried to break drug-dependence, both on their own and with professional help [79-80]. TTM consists of the Stages of Change, Processes of Change and Decisional Balance [81]. The primary research on TTM was done on smokers and shows that a smoker passes through these stages on average four times before they quit smoking. In TTM it is assumed that many people with substance addiction have not yet decided on or committed to change. Therefore interventions should be adjusted to the persons´ current level of readiness. Being aware of a patients readiness could be regarded as a part of the clinician´s task to enhance motivation to change [82].

The TTM of health behavior change is a five-step process and the stages, between which individuals may oscillate before achieving complete change, include pre-contemplation, contemplation, preparation, action and maintenance [47, 83-84]. A unique feature of the construct is the ability to explain relapses, a common occurrence in behavior change attempts [85]. At the precontemplation stage, an individual may or may not be aware of a problem and has not thought about changing his/her behavior. From the pre-contemplation to the contemplation stage, the individual develops a desire to change behavior. During the preparation stage, the individual intends to change behavior within a near future, and during the action stage, the individual begins to exhibit new behavior consistently. An individual finally enters the maintenance stage once s/he exhibits the new behavior consistently over six months [84].

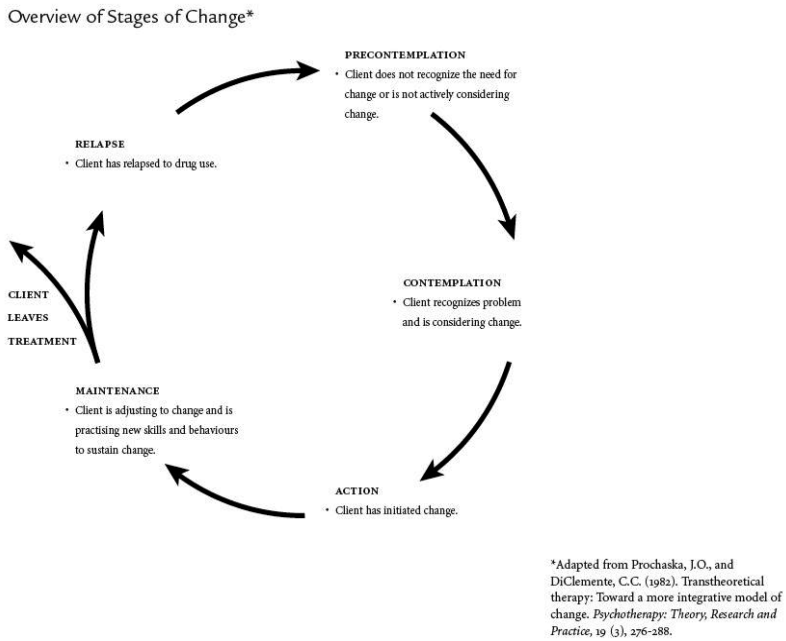

Figure 1. Overview of the Stages in the Transtheoretical Model (TTM) of health behavior change

2.4.4 Self-efficacy

A pedagogical alternative to the TTM is to elucidate patients' self-efficacy and motivation. The patients estimate their desire, ability and readiness on a Visual Analog Scale (VAS) where 1 is low and 10 is high. For example, 1 to 3 on the VAS-scale could be compared to the TTM stage of pre-contemplation; 4 to 6 could be compared to contemplation and 7 to 10 to preparation, action and maintenance [86]. This approach examines the patients' motivation, confidence and ability to perform the behavior change. By asking these questions the clinicians acquire knowledge about how to prioritize the work with the patient. For example, if the patient has high desire and low ability it is suitable to work to increase the patient's degree of readiness for change.

How important for you is it to quit smoking?

Desire

1	2	3	4	5	6	7	8	9	10

How do you rate your ability to quit?

Ability

1	2	3	4	5	6	7	8	9	10

How ready are you to quit?

Readiness

1	2	3	4	5	6	7	8	9	10

Figure 2. Explanation of how to use the questions about desire, ability and readiness according to a Visual Analog Scale (VAS)

Adapted from the Swedish National Quit Smoking Line
http://www.slutarokalinjen.org/

The MI principle of supporting patients self-efficacy draws on Albert Bandura's load-bearing concept in social learning behavior theory, which focuses on reciprocal interaction between the environment, the individual, and behavioral factors [87-88]. Self-efficacy could be defined as one's confidence in performing a particular behavior and in overcoming barriers to that behavior. Self-efficacy aims to strengthen a person's own capability to change a negative behavior and is primarily related to four factors. 1) *Enactive Mastery Experience*: Individual's prior success in changing behavior which motivates realization of a new expected performance. Self-satisfaction occurs when a person achieves important goals and becomes a cue for an individual's confidence. 2) *Vicarious Experience:* By observing others in the same situation and with the same challenge; for example, how they had managed to handle the problem of quitting smoking. 3) *Verbal Persuasion:* Outside sources of persuasion. 4) *Physiological and Affective States:* The individuals' physical and mental experience of changing behavior. Negative experiences of a behavior change, for example abstinence with smoking cessation, often decreases self-efficacy [87, 89]. The capacity in human control is central in human lives and it is individuals' belief in their own capabilities that is of importance.

"people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true" [87] (p. 2)

2.5 CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Chronic obstructive pulmonary disease (COPD) is now the fourth most common cause of death in the world and continues to increase in the developing countries. The World Health Organization (WHO) expects COPD to be the third most common cause of death in the world by 2020 [90]. The mortality rate varies in different countries, where it is related to the prevalence of smoking in the population. Mortality is high in China, Mongolia, Eastern and Central Europe, the United Kingdom, Ireland, Australia and New Zealand [91]. In Sweden, it is estimated that 8% of the population over 50 years of age suffer from COPD, and 25-30% of smokers develop the disease, with increased risk in higher ages. About 50% of smokers above 75 years of age are effected by COPD [92]. The disease costs Swedish society more than 1.1 billion USD per year [93].

COPD is a chronic, disabling and slowly progressing disease affecting the respiratory system with symptoms such as coughing, phlegm and increasing dyspnea [15]. COPD is frequently under-diagnosed, undertreated and the substantial morbidity is often underestimated by health-care professionals, providers and patients [94]. Quality of life is impaired and patients with respiratory failure need continuous oxygen treatment [95].

The definition of COPD is based on spirometry i.e. the ratio between forced expiratory volume in 1 second (FEV_1) and the highest value of forced vital capacity (FVC) or slow vital capacity (SVC). Emphysema and chronic bronchitis are not included in the definition of COPD, though small airway disease (obstructive bronchiolitis) and parenchymal destruction (emphysema) are described as contributors to the chronic airflow limitation characteristic of COPD [96]. The airflow limitation is caused by airway inflammation with mucosal oedema, increased airway secretion and airway remodeling leading to increased airway resistance and emphysema, which alters the mechanical properties of the lungs. All these factors together result in airway collapse during expiration and airway obstruction [15].

COPD is also a systemic disease with manifestations from organ systems other than the lungs. Co-morbidity such as diabetes, heart failure, osteoporosis, periodontitis, muscle weakness, cognitive dysfunction, intense fatigue, malnutrition and severe depression are often present for patients suffering from moderate to severe COPD [97-98].

A major problem for patients with COPD is dyspnea , often the symptoms that affect daily life as the major determinant of health status [99]. Patients with COPD, when compared to healthy subjects, spent less time standing and walking and more time sitting and lying down[100]. It has also been shown that prevention of underweight is important since weight loss is known to affect the progression of the disease [101-102]. Further, people with severe COPD often experience a psychosocial disability and social isolation [103]. They also expressed that their emotions vacillated between having a meaningful or meaningless life or even feeling a death wish [104]. People with COPD also expressed a feeling of guilt and shame due to the self-inflicted disease associated with smoking habits [105-106].

The most common cause of COPD is tobacco-smoking, although the disease may also result from occupational exposure, particularly in the developing countries [107-108] Indoor air pollution from biomass fuel smoke is a major health concern in the developing world, contributing significantly to the burden of COPD-related diseases in women [109]. The causal relationship between tobacco smoking and COPD was established in the 1970s, showing that prevention of the rapid decline in lung-function was influenced by smoking cessation [110]. Those who quit smoking did not regain lung-function but the subsequent loss of lung-function was parallel to non-smokers. It could be assumed that the progress of the disease reflects the progress of emphysema. However, a number of studies have shown that smokers with no or only minor symptoms may have developed significant emphysema [111-113]. At a group level, smokers with severe emphysema have impaired lung-function compared with smokers with mild emphysema [114].

The fast decline of lung-function over time is an important feature in smokers who develop COPD. The annual decline of FEV_1 in healthy, middle-aged non-smokers is 25-30 milliliters [110, 115] whereas the additional annual loss for smokers is on average 10-20 milliliters [116]. There is an inter-individual variation and there are smokers who may have an annual decline of FEV_1 of 60 milliliters or even more than 100 milliliters, resulting in severe functional decline. Frequent exacerbations increase the decline in lung-function over time and are associated with a poor prognosis [117].

2.6 NURSE-LED COPD CLINICS

The Swedish National Board of Health and Welfare has developed guidelines and compiled quality indicators for the care of patients with asthma and COPD in primary health care [14]. Based on these quality indicators, criteria for approved nurse-led COPD-clinics have been formulated, including structured investigations with measurements according to medical guidelines, patient education, smoking cessation and regular follow up visits. The recommended time for a first consultation is one hour. The objectives are to achieve an early diagnosis and involve the patient in care and treatment. The criteria were published in 2008 [118], and are a further development of those published in 1998 [119]. Specific measurements at COPD nurse-led clinics are length and weight, peak expiratory flow (PEF) spirometry with reversibility test and

pulsoximetry before and after exertion. In Sweden 87% of the primary health care clinics currently have an asthma/COPD nurse [120].

In the content of the self-management education at nurse-led COPD clinics described in the next paragraph, it has to be made clear that not all of these educational issues should be provided to all patients and not all in one consultation. Thus, self-management should be tailored for each patient's needs and the nurse should be aware of what kind of knowledge, support and problems that may be of importance for persons with COPD. When a patient needs instruction, counseling and support on a level that is not within the nurse's competence, the nurse is responsible for referral of the patient to other professionals, e.g. a physician, a physical therapist, dietician, occupational therapist or a medical social worker.

It is important to plan the consultation together with the patient and to establish an individual treatment plan in collaboration with the patient, nurse and physician. The treatment plan could include agreed goals, actions on self-management and smoking cessation, how patients should adjust medication on exacerbation, how to recognise an exacerbation and when to consult the nurse or the physician. The content of self-management education could be: smoking cessation, a description of the anatomy and physiology of the airways in association with the effects of COPD, explanation of the spirometry outcome to the patient, optimization of pharmacological treatment and control of the inhalation technique, instructions on the coughing technique to prevent infections and exacerbations, instructions on how patients should deal with acute exacerbations, assessment and instruction of breathing technique and relaxation, dialogue on physical activity and exercise, dietary counseling, psycho-social dialogue, and counseling on infection prevention [121-123].

It is obvious that self-management is crucial and requires resources and this is supported in several studies: Being able to manage symptoms was one of the most crucial aspects in everyday management for patients with COPD [124]. Disease-specific education delivered by certified COPD educators increased knowledge among patients with COPD [125]. Specialized COPD nurses in PHCC had a positive impact on patients' exacerbations [120]. Self-management programs showed a reduction in hospital admissions [126]. Further, it has been concluded that changing patient behavior and ensuring maintenance are complex processes requiring time [126] and that COPD patients in PHC need structured programs including smoking cessation, realized by specially trained staff [127].

2.7 RATIONALE FOR THE THESIS

The leading causes of morbidity and mortality are attributed to life style behaviors such as physical inactivity, poor dietary habits, tobacco use, and alcohol consumption. For patients with chronic diseases there is often a need to change behavior to maintain QoL. At nurse-led clinics for patients with chronic diseases the purpose is to support patients to live as satisfying lives as possible, in spite of ill health. Self-management education and smoking cessation are crucial ingredients in such support. Good communication skills in supporting patients to life style changes could thus be one of the most important "treatment" tools to decrease the risk of progression of the disease.

However, behavior change communication and smoking cessation are difficult. The majority of COPD-patients feel ill both physically and psychologically, and they have

often a feeling of fear, guilt and shame that makes communication an even bigger challenge. Even if health care professionals have been trained in behavioral change communication, it has been shown that it is not easy to change an established professional behavior. The challenge is to change communication style from an authoritarian expert approach to a patient empowerment approach.

Nurses working with these patients need to have disease-specific knowledge and knowledge in medical treatment but also in a patient-centered and theory-based communication in order to be as professional as possible when supporting patient in self-management and smoking cessation.

Therefore there is a need for more knowledge about how communication, self-management and smoking cessation is performed in order to manage the complexity of the care of patients with COPD. Such knowledge could form the basis for development of better self-management education and smoking cessation for patients with chronic diseases and for patients with COPD.

3 AIMS

The general aim of this thesis was to investigate the behavioral change communication between nurse and patient at nurse-led COPD clinics in primary health care focusing on communication in self-management education and smoking cessation for patients with COPD.

The specific aims were:

- to explore the structure, content in communication and self-management education, in patients' first consultations at nurse-led chronic obstructive pulmonary disease clinics in primary health care. (I)

- to describe to what extent registered nurses use Motivational Interviewing in smoking cessation communication over time at nurse-led chronic obstructive pulmonary disease clinics in primary health care. (II)

- to examine smoking cessation communication between patients and registered nurses, with a few days of MI based education, in consultations over time at nurse-led chronic obstructive pulmonary disease clinics in primary health care. (III)

- to examine the effects of a structured educational intervention at a nurse-led primary health care clinic on quality of life, knowledge about chronic obstructive pulmonary disease and smoking cessation in patients with chronic obstructive pulmonary disease. (IV)

(Henceforth the studies will be referred to in the text by their Roman numerals)

4 MATERIALS AND METHODS

4.1 DESIGN

This thesis is based on two separate data-gathering procedures, one based on video filmed consultations resulted in Papers I, II, III, the other being an intervention resulting in Paper IV. The studies were conducted between 2004 and 2008 at nurse-led COPD-clinics in Swedish Primary Health (PHC).

The designs used were:

- Explorative observational study of patients' consultations at nurse-led COPD clinics (I).
- Prospective observational studies with structured quantitative and qualitative analyses of nurses' and patients communication in smoking cessation (II, III).
- Experimental design, a comparison of conventional treatment (control group) and an educational intervention to support patients' self-management (intervention group) (IV).

Table 1. Overview of study designs and research methodologies

Paper	Design	Sample	Data collection	Data analyses
I	Explorative observational	30 patients consecutively selected and 7 COPD[1]-nurses	Videotaped consultations	CM[2] and judgment of self-management education
II	Prospective observational	13 patients consecutively selected and 6 COPD[1]-nurses	Videotaped consultations	MITI[3] coding instrument global scores, behavioral scores and summary scores
III	Prospective observational	13 patients consecutively selected and 6 COPD[1]nurses	Videotaped consultations	MITI[3] global scores, behavioral scores and CLAMI[4]
IV	Experimental	52 (consecutively selected) patients randomized into two groups, intervention and control	Questionnaires: Knowledge about COPD[1] smoking habits and SGRQ[5]	Mann-Whitney U test, Fisher's exact test. Clinical relevance of 4 weighted units

[1] COPD = Chronic obstructive pulmonary disease
[2] CM = Consulting Map
[3]MITI =Motivational Interviewing Treatment Integrity scale
[4]CLAMI = Client Language Assessment in Motivational Interviewing
[5]SGRQ =St. George`s Respiratory Questionnaire

4.1.1 Papers I, II and III

Papers I, II and III are based on videotaped consultations at nurse-led COPD clinics.

4.1.1.1 Inclusion criteria

In compliance with the national criteria for approved asthma and COPD clinics in Swedish PHCC, the inclusion criteria were: specially trained nurses who spend more than 0.5 hour/week/1000 inhabitants caring for patients with asthma and COPD, a physician responsible for the unit, one-hour pre-scheduled appointments, spirometry with reversibility, pulsoximetry, and structured assessment with patient education [128]. The nurses were also required to have at least two years' experience as a COPD-nurse.

4.1.1.2 Procedure

The PHCCs, were located in both rural and urban areas in central and southern Sweden. The clinic was included when the COPD nurse had given oral consent and the clinic manager had given written consent. Patients were consecutively selected upon referral to COPD-nurses and prior to the first consultation they were informed and asked to participate by the nurse. The researcher installed the camera in the room, but was not present during the consultation, which was recorded in its entirety. A questionnaire covering demographic background data and smoking habits (number of cigarette packs/year) was distributed by one of the researchers (EÖE), and filled in by the patients at the clinic, just before the first (I, II, III) and directly after the third consultation (II, III).

4.1.2 Paper I

4.1.2.1 Sample

Seven COPD-nurses, working at seven PHCC's, contributed two to eight patient consultations each to the sample. The patients were included if they had a suspected COPD, COPD stage 1 (mild) to stage 4 (very severe), according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria [15, 129]. The first consultations of thirty patients were studied. Twenty-eight of the included patients had COPD and/or were smokers and were scheduled for a follow-up visit. Nurse and patient background characteristics are displayed in Table 2 and 3.

Table 2. Characteristics of the nurses (n=7)

	Paper I
Age: median (range)	51 (45-58)
Gender: female/male	6 / 1
University education in COPD[1] 0 / 7,5 / 15 / 22,5 ECTS[2] credits	1 / 1 / 4 / 1
Years working as asthma/COPD[1] nurse median (range)	8 (5-13)

[1]COPD=Chronic obstructive pulmonary disease
[2]ECTS=European Credit Transfer System

Table 3. Characteristics of the patients (n=30)

	Frequency	Female/Male
Patients	30	22 / 8
Age (years): median (range)	58 (26-78)	54 / 65 (26-66 / 51-78)
Marital status		
living together	21	15 / 6
living alone	9	7 / 2
Occupation		
employed	15	12 / 3
retired	15	10 / 5
Education		
compulsory school	8	6 / 2
upper secondary school	19	15 / 4
university level	3	1 / 5
Smoking history		
smokers	22	18 / 4
former smokers	8	4 / 4
Severity of COPD[1] (GOLD[2] criteria)		
no COPD, former smoker	2	2 / 0
no COPD, smoker	7	6 / 1
stage 1	12	9 / 3
stage 2	5	3 / 2
stage 3	2	1 / 1
stage 4	2	1 / 1

[1]COPD=Chronic obstructive pulmonary disease
[2]GOLD= Global Initiative for Chronic Obstructive Lung Disease

4.1.2.2 Instruments

The Consulting Map (CM) is a method for analyzing videotaped consultations, designed to map structure, content and communication styles, emphasizing the importance of involving the patient in symptom management. CM was introduced by Pendleton and co-workers. A number of items are used with the aim of exploring whether the consultation is patient-oriented [130]. These items were supplemented with: an investigational phase (one item), an educational phase (three items about education and two items about smoking cessation), and also one miscellaneous item. The adapted CM included 17 items divided into four phases: 1) reason for the consultation; 2) investigations; 3) education and smoking cessation, and 4) conclusion including choosing appropriate actions together with the patient. During the analysis, the tape was stopped every 15 seconds and the content was analyzed according to the CM. To measure duration of each item in the CM and consultation patterns, **t**he proportion of time spent for each of the 17 items in the CM was documented by counting periods of 15 seconds for each item during the consultation [130]. The phases and items of CM are displayed in Appendix 1.

4.1.2.3 The content of self-management education

The content of the nurses' self-management education was judged on the provision of important and relevant information and self-management education based on the severity of the COPD-diagnosis, the patient's smoking habits and the performance and interpretation of investigations according to current accepted standards [15, 128].

Important concepts for COPD self-management education are spirometry, pulsoximetry, patho-physiology, pharmacological treatment, inhalation, coughing and breathing technique, acute exacerbations, smoking cessation, infection prevention, physical activity, psychosocial counseling, dietary counseling and finally conclusions in a written individual treatment-plan [15, 128]. Description of the concepts is displayed in Appendix 2.

4.1.2.4 Validity and Reliability

Each videotaped consultation was assessed and rated by one of the authors (EÖE). The supplemented CM was validated for eight videotaped consultations by the research group. To safeguard credibility, four recordings were examined independently by the researchers, three nurses and one physician, who arrived at identical analyses for the second, third, and fourth phases and similar or related analyses of the first phase. Validity for the content of self-management education and inter-observer reliability were established for 15 videotaped consultations, and were each assessed twice at two months interval by one of the authors (EÖE).

4.1.2.5 Statistics

Data are presented as frequencies and continuous variables with abnormal distribution such as median and range and 25th, 50th (median), 75th percentiles and range.

4.1.3 Papers II and III

4.1.3.1 Sample

Paper II and III were based on two consultations with 13 smokers (session one and three of three visits, n=26) at nurse-led COPD clinics in Swedish primary health care clinics (PHCC). The patients were included if they had a suspected COPD, COPD stage 1, (mild) to stage 4 (very severe), according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria [15, 129]. The consultations were conducted by six COPD-nurses, working at six PHCC. The time between the first and third consultations varied from three to eight months depending on local routines and took place from March 2006 to April 2007. Each nurse contributed between one and four patients. Nurses, patient and background characteristics are displayed in Table 4 and 5.

Table 4. Characteristics of nurses (n=6)

	Paper II and III
Age: median (range)	50 (45-60)
Gender: female/male	6 / 0
University education in COPD[1] 0 / 7,5 / 15 / 22,5 ECTS[2] credits	0 / 0 / 5 / 1
Years working as asthma/COPD[1] nurse median (range)	11 (5-14)

[1]COPD=Chronic obstructive pulmonary disease
[2]ECTS=European Credit Transfer System

Table 5. Characteristics of the patients (n=13)

	Frequency	Female/Male
Patients	13	11 / 2
Age (years): median (range)	53 (27 / 78)	52 / 74 (27- 65 / 70-78)
Marital status		
living together	7	5 / 2
living alone	6	6 / 0
Occupation		
employed	9	9 / 0
retired	4	2 / 2
Education		
compulsory school	4	3 / 1
upper secondary school	9	8 / 1
university level	0	0 / 0
Severity of COPD[1] (GOLD[2] criteria)		
no COPD	2	2 / 0
stage 1	7	7 / 0
stage 2	2	1 / 1
stage 3	2	1 / 1
stage 4	0	0 / 0

[1]COPD=Chronic obstructive pulmonary disease
[2]GOLD= Global Initiative for Chronic Obstructive Lung Disease

4.1.3.2 Instruments

To analyze the videotaped consultations the behavioral coding system Motivational Interviewing Treatment Integrity (MITI) scale [73] and the Client Language Assessment in Motivational Interviewing (CLAMI) segment [131] were used. MITI measures the practitioner's use of motivational interviewing and CLAMI assesses the patients' talk within a MI session and is designed to be compatible with MITI. The coders judged the nurses' and patients' verbal communication with emphasis on a specific coding task, the Target Behavior Change (TBC). In the present study smoking cessation communication was coded throughout the entire consultation. Non-verbal communication was not analyzed.

MITI

Two different types of coding procedures are applied in MITI, "global scores" and "behavioral codes" (Figure 3). The Global score captures the impression of the clinician's target behavior communication with regard to five global dimensions: Evocation, Collaboration, Autonomy-Support, Direction and Empathy, on a five-point Likert-scale, ranging from one (low) to five (high). All dimensions were assessed as individual parameters, whilst Evocation, Collaboration and Autonomy-Support were also averaged together, yielding an "MI-spirit" score indicating the general impressions of the three parameters. Behavior codes imply registrations of the frequency of specific utterances during the recorded session. There are five behavior codes; Giving information, Questions, Reflections, MI Adherent and MI Non-adherent. The Questions code includes two sub-codes, closed and open questions, and the Reflection code includes Simple and Complex Reflections. The coder does not judge the quality or appropriateness of the utterances, but simply counts the number of different utterances exhibited by the nurse [73].

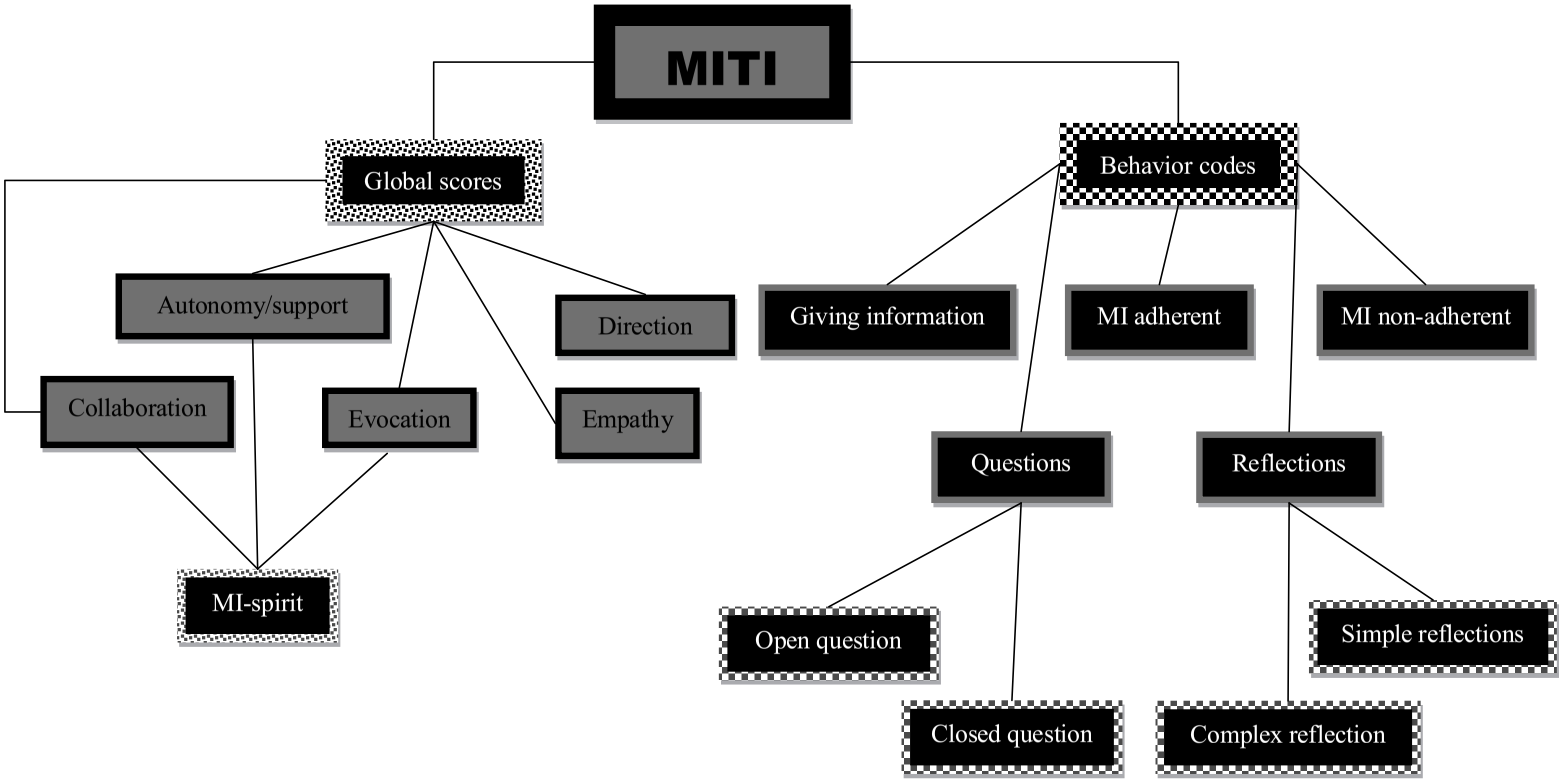

Figure 3. Concept map for motivational interviewing treatment integrity (MITI) scale

CLAMI
Within CLAMI, language moving in the direction of change is termed "change talk" whilst language indicating a movement away from change is called "sustain talk" coded in four categories: 1) Reason - with sub-codes: Desire, Ability, and Need, 2) Other, 3) Taking Steps, and 4) Commitment. Every time an example of one of the categories occurs in patient talk, the category is recorded as change (+) or sustain (-) talk. If the patient's smoking cessation talk is neither toward nor away from the TBC it is coded in a fifth category Follow/Neutral [73].

Examples of MITI behavior codes and CLAMI categories from a few utterances in smoking cessation communication drawn from a third consultation:
Nurse: *So how do you anticipate the future, then? (open question)*
Patient: *I will quit smoking (commitment +)*
Nurse: *How do you plan to go about to do that, it's a bit interesting to hear, will it happen or will it…. (open question)*
Patient: *I think that it will evolve little by little, it will happen gradually (other +)*
Nurse: *It does not get so hysterical (complex reflection)*
Patient: *The cigarettes did influence a lot before (neutral)*
Nurse: *That is very good – excellent (MI Adherent)*

4.1.3.3 Speaking time

The division of speaking time between the nurse and the patient was estimated at three levels; 1) if the nurse spoke most of the time, 2) if the time was equally divided between nurse and patient, and 3) if the patient spoke most of the time.

4.1.3.4 Procedure

The coding was undertaken at the Motivational Interviewing Coding (MIC) Laboratory at Karolinska Institutet in Stockholm by three qualified coders, using MITI 3.0 [73] and CLAMI segment [131]. The coders have more than 80 hours of initial training, 40 hours for MITI and 40 hours for CLAMI, in accordance with the recommendations of the University of New Mexico research group, followed by 3-hour training sessions every fortnight to achieve precision and quality in the coding. One coder listened to the entire consultation for both MITI global score and behavior codes [73] and another for the CLAMI categories.

4.1.3.5 Validity and Reliability

MITI has proved to be a reliable tool for evaluating the use of MI [132-133], and has shown good validity with regard to in-session behavior and MI skill development over time (entry-level competence and post-MI training) [134-135]. It has also been recommended as a way of evaluating MI training [132, 136-137]. There were no reliability and validity data found for CLAMI and for the patients' talk in the Motivational Interviewing skills Code (MISC) version 2.1 [71], from which CLAMI is developed, apart from a report on the Swedish version of CLAMI that showed good to excellent inter-rater reliability for all CLAMI variables [138]. (The MISC was developed to assess motivational interviewing during clinical interaction in which clinical behavioral change is desirable). The MISC 2.1 has been used in research on clients' talk, with results that highlight the relationship between counselors' MI-skills and clients' change talk [139].

To safeguard reliability, five video-taped consultations (20% of the total data set) were independently coded by two coders for both MITI and CLAMI, and inter-rater reliability was calculated with the intra-class coefficient (ICC). ICC takes into account the frequency of equal variable ratings for the coders, as well as possible systematic differences between the coders. The coder ICC: for MITI (both global scores and behavior codes) showed coefficients ranging from 0.86 to 1.0, "excellent" agreement, for CLAMI "taking steps" 0.50, "acceptable" agreement and for the remaining CLAMI categories the coefficients ranging from 0.75 to 1.0, "excellent" agreement (Cicchetti, 1994).

4.1.3.6 Statistics

All statistical analyses were performed using Statistical Package for Social Sciences (SPSS) 17.0. Coded data for the MITI global scores were treated as ordinal data. The MITI Behavior codes and CLAMI categories data were treated as interval data. Frequencies and continuous variables with normal distribution are presented as mean, standard deviation (SD) and range. Differences between the two consultations, separate variables in MITI and CLAMI and the sum of MITI global scores, behavior codes and CLAMI categories were analyzed using the Wilcoxon rank sum test.

4.1.4 Paper IV

4.1.4.1 Sample

The study population consisted of all patients with suspected COPD (n=110) who were referred to the COPD nurse at a Swedish PHCC during a ten months period. The patients were included in all stages of COPD, from stage 1 (mild) to stage 4 (very severe), according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria [15, 96]. Patients with diagnosed severe mental disorders were excluded. The 52 included patients, whereof 26 women, were matched based on gender and severity of COPD, and then randomized into the intervention or control group (Table 6). The mean age for the intervention group was 66 years (SD=9.4) and 67 years (SD=10.4) for the control group. There were 16 smokers (6 women) in the intervention group and 14 (7 women) in the control group. Co-morbidity as cancer, diabetes and heart disease was similar in the two groups.

Table 6. The division of the COPD stages among the patients, (n=52)

PATIENT GENDER AND COPD[1] STAGES	INTERVENTION GROUP	CONTROL GROUP	TOTAL
Women mean age:68 (SD=9.7)	(n=13)	(n=13)	(n=26)
COPD stage 1	2	3	5
COPD stage 2	3	3	6
COPD stage 3	3	2	5
COPD stage 4	5	5	10
Men mean age:66 years (SD=11.4)	(n=13)	(n=13)	(n=26)
COPD stage 1	3	2	5
COPD stage 2	6	6	12
COPD stage 3	3	3	6
COPD stage 4	1	2	3
Total	26	26	52

[1]COPD=Chronic obstructive pulmonary disease

4.1.4.2 Instruments

St. George's Respiratory Questionnaire (SGRQ) [140-141] and a questionnaire specifically developed for this study were used for data collection. SGRQ is a disease-specific instrument designed to measure impact of respiratory symptoms on overall health, daily life and perceived well-being. The instrument has shown good validity and reliability [142]. Results are reported in four sections: symptoms, activities limited by breathlessness, psycho-social impact and comprehensive impact as a basis for the assessment of QoL. Each section is presented as a weighted score from 0 to 100, with higher scores indicating lower quality of life. In addition a questionnaire contained questions on patient characteristics, such as gender, age, marital status, education and knowledge about COPD and smoking habits. Patients' knowledge was measured by a simple question: "How do you rate your knowledge about COPD?" and the answer was given on an ordinal scale, ranging from very good to none. Data on smoking was collected by the question "Do you smoke?" with dichotomous response alternatives (yes/no).

4.1.4.3 Procedure

After referral to the nurse-led COPD clinic, patients were assessed by spirometry and those who were diagnosed with COPD and fulfilled the inclusion criteria, were invited by the nurse to participate in the study. All the patients who agreed to participate were scheduled for the first and last visits to the COPD clinic, with a three- to five-month interval. At these visits all patients responded to the two questionnaires. The patients in the intervention group had, in between these visits, two one-hour visits for self-care education, whereas the patients in the control group were given conventional care that included a first visit to the nurse with spirometry and a follow up visit to the physician according to clinic routines. The same nurse (EÖE) was responsible for all consultations. After the termination of the data collection phase, patients in the control group were invited to self-care educational visits to the COPD nurse.

4.1.4.4 Intervention

Patients in the intervention group received education with an emphasis on self-management ability and supporting the individual, based on his or her unique requirements and abilities to cope with disease and treatment [102, 143-144]. The educational visits were based on motivational dialogue, tailored for each patient, based on severity of illness, age, intellectual capacity and life style, with the following main components:

- Description of the COPD disease anatomy and patho-physiology
- Spirometry, pulsoximetry, PEF
- Explanation of pharmacological treatment, how patients should deal with acute exacerbations
- Control of the inhalation technique
- Simpler coughing- and breathing technique and relaxation.
- Smoking cessation, the most crucial matter if the patients were smokers
- Dialogue on physical activity, diet, psychosocial health
- Vaccination
- A summary of the consultation in a written individual treatment plan in collaboration with the patient

The intervention programme was accomplished in collaboration between patients, the COPD nurse and the physician. When needed, a dietician, a medical social worker, a physical therapist and an occupational therapist were consulted. In the intervention group there were 16 patients who had their medication changed. Three patients had an extra visit to the physician; two were referred to a medical social worker, two to a dietician, physical therapist and occupational therapist respectively. In the control group, no patients had their medication changed. One patient had an emergency visit to the PHCC, one had a telephone consultation and one had a planned visit to the physician.

4.1.4.5 Statistics

Hypothesis testing of effects on QoL was performed by the Mann-Whitney U test. Effects on smoking cessation and patients' knowledge about COPD were computed by Fisher's exact test. Significance levels at $p<0.05$ were accepted as statistical significant, and clinical relevance was accepted if there was a difference of the means within and between groups of four weighed units, which is in accordance with the SGRQ manual [145].

4.1.5 Ethical consideration

All studies were approved by the Research Ethic Committee. Permission was given by the managers and physicians in charge at the PHCC's and formal consent was obtained. Video recording as research method can be very disclosing and perceived as a threat to integrity of those involved. Therefore it is important to protect the identity of the participating patients and nurses. The clinical manager, nurses and patients were provided with written and oral information about the studies and all patients gave both oral and written consent. The study participants were also informed about the voluntary nature of their participation, and that they could withdraw from the study at any time without any further explanation and with no adverse effect on their subsequent care or treatment. To guarantee non-violation of nurse and patient confidentiality, only the researchers and coders had access to the material and have examined the videotaped consultations carefully, keeping names and identifiable data confidential [146-148].

5 RESULTS

5.1 PAPER I

5.1.1 Structure of the consultations

The patients' consultations at the COPD-clinic lasted for mean: 37:53, median 37:45 (21:00-57:00) minutes. In all 30 consultations, the nurses performed spirometry before and after administrating a bronchodilator. The majority of the consultations had the same structure - in 24 of 30 they began with investigations of height, weight and spirometry and ended with planning for interventions. The middle part, the interval between pre- and post-bronchodilator spirometry was used to communicate with the patients about symptoms, counseling about COPD, self-management and smoking cessation.

5.1.2 Content of the communication

5.1.2.1 Time utilized for the different phases

During the **first phase**, the reason for consultation, the communication mainly concerned the history of problems (median 3:15 (range 1:00-9:00) minutes) and almost no time was spent on patients' ideas 0 (0:00-1:00) and fears 0 (0:00-1:15). The time spent during the **second phase** on the investigation including PEF, height, weight and pulsoximetry was 13:15 (5:15-20:45) minutes. The **third phase,** the education and smoking cessation, comprised educational level 1 (4:23 (1:00-6:00) minutes), level 2 (0:53 (range 0:00-8:30) minutes), support for smoking cessation level 1 (2:45 (range 0:30-11:15) minutes) and level 2 (2:00 (1:00-10:45) minutes). The **fourth phase** was to choose appropriate action with the patient. This section was divided between shared understanding (0:15 (0:00-1:30) minutes), shared responsibility (0:00 (range 0:00-0:45) minutes) and action taken **(**2:53 (0:15-9:45) minutes) (Table 7).

5.1.3 Content and performance of self-management education

The nurses´ investigations and self-management education in the consultations (n=30) are displayed in Table 8. Spirometry was correctly performed with usable results in all consultations except one. Pulsoximetry was performed in four consultations both at rest and during exercise. Education on patho-physiology and physical activity was provided in 16 consultations. Teaching about pharmacological treatment and control of inhalation technique was performed in nine consultations, in six consultations this kind of teaching was deemed irrelevant, whilst in 13 cases it was not performed, even though relevant. None of the 28 consultations with a scheduled follow-up visit to the COPD-nurse ended with a summary of the agreement with the patient, choosing appropriate action or shared understanding in a written treatment-plan.

Table 7. Time in minutes used for each phase and issue in the CM during COPD-consultations (n= 30)

Phases and issue in the consultations	**Duration of time**			
	25th Percentile	**50th Percentile**	**75th Percentile**	**Range**
Total time for each consultation	29:41	37:45	42:11	21:00 – 57:00
Miscellaneous	0	0:15	0,45	0:00 – 5:00
Phase 1 (total)	**3:23**	**5:30**	**9:57**	**1:30 - 30:15**
A. History	2:08	3.15	5:04	1:00 – 9:00
B. Aetiology	1:15	1:45	2:19	0:00 – 4:45
C. Patient's Ideas	0:00	0:00	0:15	0:00 – 1:00
D. Patient's Fears	0:00	0:00	0:00	0:00 – 1:15
E. Continuing problems	0:00	0:00	0:00	0:00 – 1:30:
F. Other problems	0:00	0:30	2:00	0:00 – 7:15
G. Risk factors	0:00	0:00	0.19	0:00 – 5:30
Phase 2 (total) H. Investigations	**9:00**	**13:15**	**16:04**	**5:15 – 20:45**
Phase 3 (total)	**3:45**	**10.01**	**14:45**	**2:30 - 36:30**
I. Education level 1	2:30	4:23	7:00	1:00 – 6:00
J. Education level 2	0:00	0:53	1:30	0:00 – 8:30
K. Education level 3	0:00	0:00	0:00	0:00 – 0:00
L. Support patient for smoking cessation level 1 (n=22)	0:30	2:45	6:15	0:30 – 11:15
M. Support patient for smoking cessation level 2 (n=22)	0:45	2:00	4:15	1:00 – 10:45
Phase 4 (total)	**2:00**	**3:08**	**5:04**	**0:15 - 12:00**
N. Shared understanding	0:00	0:15	0:30	0:00 – 1:30
O. Action taken	2:00	2:53	4:34	0:15 – 9:45
P. Shared responsibility	0:00	0:00	0:00	0:00 - 0:45

Table 8. Content in self-management education in COPD-consultations (n=30)

Content in self-management education in consultations	Carried out after the nurse's judgment of relevance *	Not carried out because it was irrelevant**	Carried out to some extent	Not carried out even if it was relevant
Spirometry	29	0	1	0
Pulsoximetry	4	7	10	9
Patophysiology	16	1	1	12
Pharmacological treatment and inhalation technique	9	6	2	13
Acute exacerbations.	0	8	4	18
Coughing technique	1	6	1	22
Breathing technique	1	7	1	21
Motivational dialogue about smoking cessation	4	8	14	4
Infection prevention	5	9	0	16
Physical activity	16	2	2	10
Psycho-social counceling	0	17	0	13
Dietary counseling	4	19	3	4
Individual written treatment plan	0	2	0	28

* Discussion of a relevant subject, **or no discussion because the subject was irrelevant e.g. if the patient did not have inhalation medicine and was not going to be prescribed such. The judgments of relevant or irrelevant subject are described in Appendix 2

5.2 PAPERS II AND III

5.2.1 Smoking cessation time and distribution of speaking time

The mean duration of the entire first consultation was 43 minutes, with 15 minutes for the smoking cessation communication, i.e. 35% of the total time. In the third consultation the corresponding times were 33 minutes and 11 minutes (33%), respectively. The mean duration for all consultations (n=26) was 38:16 (SD: 10:56) minutes, with 13:14 (SD: 6:45) minutes spent on smoking cessation.

In 18 of the 26 consultations the nurse spoke more than the patient, equally represented between the first and third consultations. In seven consultations (four of them at the first visit) the nurse and the patient spoke for an equal amount of time, and in one of the third consultations, the patient spoke the most. Consultation and speaking time for each consultation are presented in Table 9.

Table 9. Consultation time and smoking cessation time in minutes

	Consultation time	Smoking cessation time
Consultation	**First consultation/Third consultation**	
A	40 / 37	21 / 16:30
B*	49 / 27	6 / 1:30
C	45 / 36	14:30 / 17:30
D	35 / 26	6 / 2
E	42 /22	17:30 / 17:30
F	39 / 30	18 / 8:30
G	27 / 29	14:30 / 11:30
H	40 / 20	21 / 18
I	31 / 55	4:30 / 10
J	57 / 52	20:30 / 10
K	48 / 31	14:30 / 6
L	53 / 36	15:30 / 5
M	54 / 38	27 / 20
Total	560 / 439	200:30 / 144

*The patient stopped smoking between the second and third consultation

5.2.2 Nurses' talk about smoking cessation

5.2.2.1 Global scores

The MITI-global scores are; how the nurse evokes patients' reasons for change, fosters collaboration and supports patients' autonomy; how the nurse maintains appropriate focus on the smoking cessation communication (Direction); and finally how the nurse shows empathy. The global score Direction rated 5 (the highest) in all 26 consultations and the remaining global scores rated between 1 (low) and 3 (medium). The mean value in the first and third consultation was for Evocation 1.38 and 1.31, Collaboration 1.77 and 2.0, Autonomy/Support 2.0 and 2.15, Empathy 2.0 and 2.23. In the MI-spirit (mean of evocation, collaboration, and autonomy/support) nurses scored 1.0 to 2.67 at the first consultations and 1.33 to 2.67 at the third consultation.

5.2.2.2 Behavior codes

The result of the MITI behavior codes showed that it was most common for the nurses to provide information, educate and give feedback (giving information) about smoking cessation during the consultation, with a mean of 14.15 at the first visit and 14.77 at the third visit. It was also common for the nurses to ask yes/no questions (closed questions), mean 8.15 and 6.15 respectively and to reflect or summarize patients' statements without adding additional points (simple reflections), mean 5.62 and 3.85 respectively. Further, the nurses gave advice without permission, confronted patients, gave orders, commanded or made imperatives (MI non-adherent behavior) with a mean of 4.92 and 5.00 respectively. It was uncommon for nurses to ask questions that allowed a wide range of possible answers (open questions), with a mean 1.23 and 0.77 respectively. The nurses seldom reflected on or summarized what the patients had said with a substantial or deeper meaning (complex reflections), mean 0.85 and 0.38 respectively, or to use MI-adherent behavior, with a mean of 0.85 and 1.46 respectively. The percentages of the total sum of the behavior codes in the first and third consultation are presented in Figure 4a and 4b.

5.2.3 Patients' talk about their smoking

The results from the CLAMI categories showed that on average three-fifths of patients' utterances followed the nurses' talk with e.g. "Sure" or "OK" and were coded in the category Follow/Neutral, with a mean of 23.54 in the first and 20.23 in the third consultation. The rest, about two-fifths of patients' utterances, were divided between the remaining CLAMI categories. Sum of Reason category, including Reason, Desire, Ability and Need, covers patients' utterances about rationale and motivation, exhibited in change talk with a mean of 2.69 in the first, 3.92 in the third consultation and in sustain talk a mean of 3.61 and 3.69 respectively. The category *Other,* including problem identification, minimization of problem and hypothetical language, showed in change talk a mean of 5.00 and 5.30 respectively and in sustain talk of 3.15 and 2.38 respectively. Concrete steps towards smoking cessation expressed by the patient, *Taking Steps,* showed in change talk a mean of 0.08 at the first, 0.54 at the third consultation. Corresponding figures for sustain talk were 0.08 and 0.24, respectively. In *Commitment* language (agreement, intention or obligation regarding smoking cessation) there were no utterances at the first consultation. In the third consultation, change talk showed a mean of 0.15 and sustain talk a mean of 0.08. The percentages of the total sum of the CLAMI categories are presented in Figure 5a and 5b.

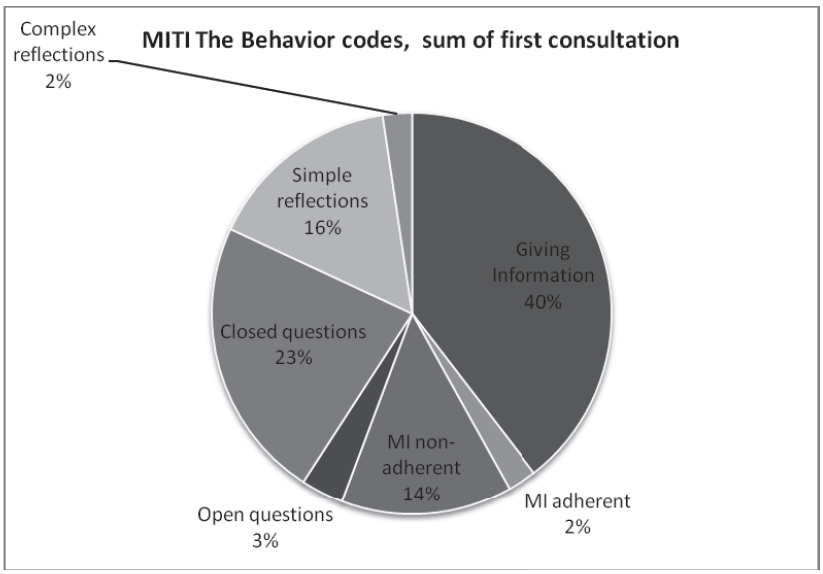

Figure 4a. The sum of the behavioral codes of the first consultation, number of utterances

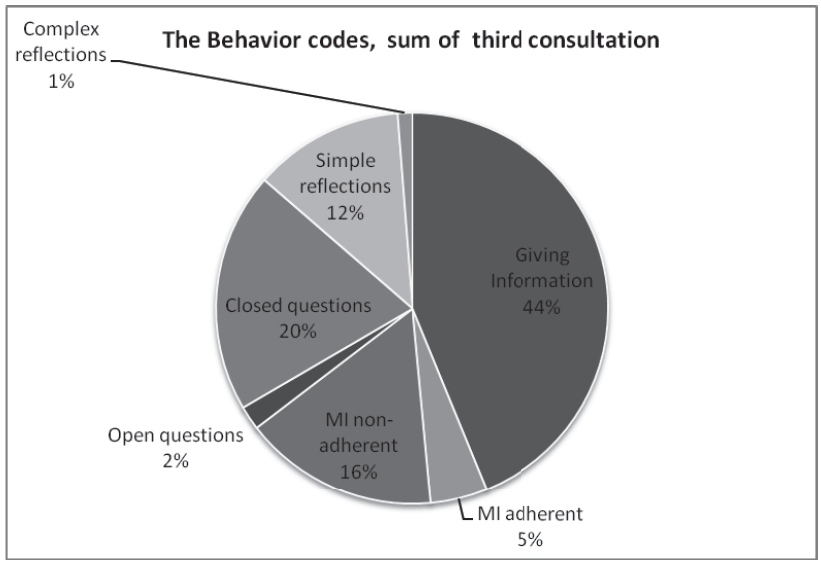

Figure 4b. The sum of the behavioral codes of the third consultation, number of utterances

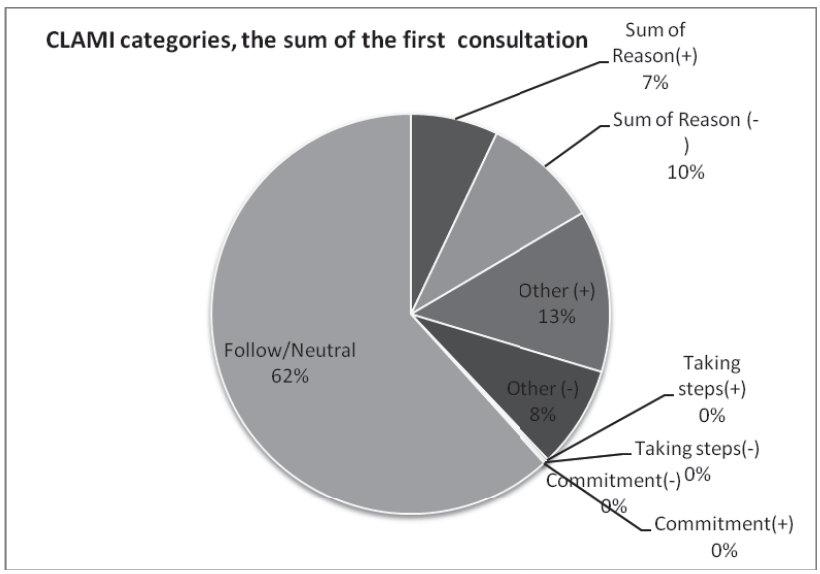

Figure 5a. The CLAMI categories, the sum of the first consultation, number of utterances

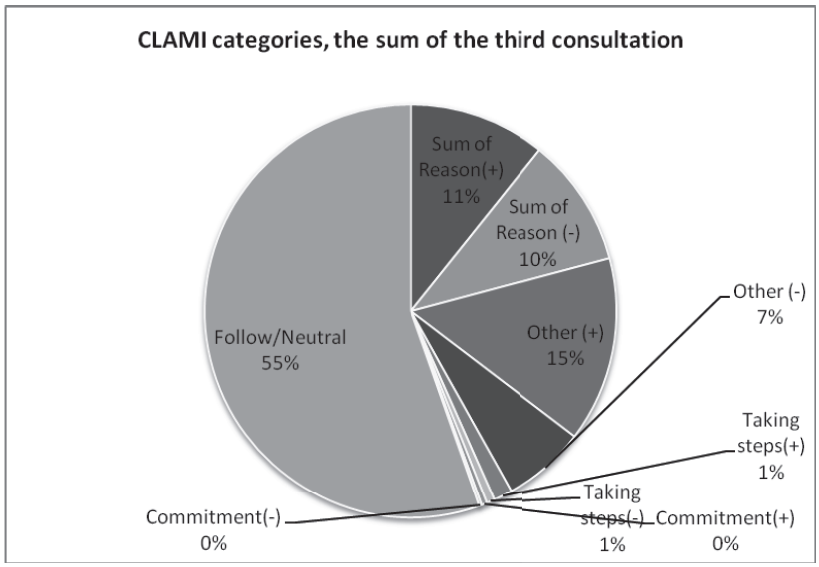

Figure 5b. The CLAMI categories, the sum of the third consultation, number of utterances

5.3 PAPER IV

5.3.1 Quality of Life

5.3.1.1 Patients' perceived symptoms

Patients in the intervention group perceived a reduction in symptoms of cough, phlegm, dyspnoea and wheezing with an average improvement of 25 weighted units from a median baseline of 53.units. In the control group there was a deterioration of 4 units from a median baseline of 54 units. The difference between the intervention and control groups was significant ($p<0.001$) and clinically relevant according to the SGRQ manual.

5.3.1.2 Patients' perceived restrictions in daily activities

Patients in the intervention group reported increased activities (e.g. managing hygiene, clearing away snow and performing physical exercise) and reduced dyspnoea. The average value of these improvements was 5.6 units from a median baseline of 42 units. The patients in the control group did not report any significant change; their values had deteriorated with 3.1 from a median baseline of 54 units. The difference between the groups was significant ($p=0.03$) and clinically relevant.

5.3.1.3 Patients' perceptions on psycho-social activities

A decreased impact of COPD of respiratory problems on psycho-social health by an average value of 3.4 units from median baseline of 19 units was noted among patients in the intervention group. There was no change for patients in the control group from a median baseline of 26 units. The difference between the groups was significant ($p=0.02$) and clinically relevant.

5.3.1.4 Patients' perceptions of quality of life

Quality of life was based on the weighted total change of symptoms, activities and psycho-social function. In the intervention group patients' QoL was improved by an average value of 8.2 units from a median baseline of 30.6, whereas no change was noted in the control group from baseline of 41.2 units. The difference between the groups was significant ($p<0.001$) and clinically relevant.

5.3.2 Knowledge about COPD

Patients in the intervention group reported an increase in perceived knowledge about COPD. Patients that reported *no knowledge* decreased from 8 to 0, *limited knowledge* decreased from 14 to 7, *good knowledge* increased from 4 to 17 and very good knowledge increased from 0 to 2. There were no such perceived improvements reported in the control group. At baseline, no difference between the groups regarding knowledge of COPD was found, but there was a significant difference post-intervention ($p<0.001$).

5.3.3 Smoking

In the intervention group 2 of 6 women and 4 of 10 men (or 37.5%) who were smokers had stopped smoking during the intervention phase. In the control group none of the 14 smokers stopped smoking. The difference between the groups was significant ($p=0.018$).

6 DISCUSSION

This thesis has shown that the communication at nurse-led COPD clinics rarely involved the patients in shared understanding and responsibility and was focused on patients' concerns, fears and worries only to a small extent. The result showed that nurses had difficulties in attaining proficiency in behavioral change communication. The smoking cessation promoted to a small extent patients' collaboration, evocation and autonomy about the reason to change smoking behaviors. The nurses supplied large amounts of information, posed closed questions and made simple reflections. Open questions and complex reflections occurred rarely. The patients' utterances in the smoking cessation communication expressed to a certain extent the reason towards smoking cessation or commitment to stop smoking. The result also showed that the number of patients who stopped smoking and patients' knowledge about the disease and their QoL were increased by structured and tailored self-management education and smoking cessation based on motivational dialogue, in collaboration with a patient, a nurse and a physician and, when needed a physical therapist, a dietician, an occupational therapist and/or a medical social worker.

6.1 SMOKING CESSATION

In the available literature, different models of communication in supporting patients to quit smoking are presented and recommended [55, 86-87, 149-151]. There are similarities in the methods and models which are all focused on empathy, open questions, reflective listening with the goal of increasing patients' self-efficacy. It is important that nurses base their communication on a model/method to increase the quality of the communication, because it is not sufficient to give information, and with good communicative qualities to support people in smoking cessation and self-management [3]. In Sweden, MI is one of the main methods recommended to be used in behavioral change communication [8, 53]. When the smoking cessation communications were analyzed in the consultations, it was found that the time for smoking cessation, central to the support of these patients, was rather limited (I II, III). There were eight consultations where the duration of the dialogue on smoking cessation lasted for less than 10 minutes (III). When MI is used in smoking cessation, the outcome is slightly more effective when long lasting (> 20 minutes) and when multiple sessions (instead of single sessions) are used [5]. Furthermore, smoking cessation counseling that lasted for 10 minutes or more and included the use of a communication model has been stated as highly relevant for behavioral change [3]. Spending only a few minutes' communication on the patients smoking habits implies that e.g. open questions and complex reflections could not be used to any large extent. One explanation for the briefness of smoking cessation communication may be that the nurses have to switch focus between disease problems, examinations (PEF, spirometry, pulsoximetry) and smoking cessation. This may make it more demanding to keep smoking cessation in focus. A further explanation for the brief time devoted to smoking cessation could be that patients needed to discuss other problems of greater importance to them, e.g. their worries of recently having received a severe disease diagnosis. However, this was not observed in our study since only limited time was devoted to talk about patients' concerns, fears and problems (I).

It has been shown that smokers try to reduce cognitive dissonance by playing down their own perceived risk of disease, or by denying and avoiding information about the

danger of smoking [152-154]. The spirometry alone could be an effective educational strategy for smoking cessation and for overcoming that cognitive dissonance. It could help smokers to be aware of the condition of their lungs. The fact that six out of 16 smokers were able to quit smoking during the intervention (IV) could be a result of combined use of motivational dialogue, information on the impact of smoking on pulmonary tissue and that the spirometry displayed the patients' decreased pulmonary capacity. This combined approach probably enforced and helped to explain patients' perceptions regarding their shortness of breath (IV). An impaired lung volume shown on the spirometry, and explained and discussed together with the patient, could support the patient in moving from pre-contemplation to action in the TTM stages, during one consultation. These findings concur with a study that showed that nurse-led screening with spirometry, combined with patient education, helped patients to stop smoking or to seriously consider stopping [155]. It has also been confirmed that smokers with a spirometry diagnosed COPD stopped smoking more often than those with normal lung function [156-159]. To show the patient a defective spirometry is a challenge, as this could be seen as a confrontation, which within a MI context counteracts the outcome of behavior change and does not adhere with the principles of MI (MI adherent) [55]. It is crucial that the spirometry result is not presented to the patient in a confrontational manner (MI non-adherent). In the empowerment concept the patient should be given the opportunity to understand the professional's view of the disease, and an objective result in form of spirometry could support such a strategy.

The large share of information provision in the consultations (I, II, III) was not surprising, since giving information is consistent with nurses' traditional counseling practice. This also corresponds with the finding that the nurses talked more than the patients during the consultation time (II, III). The provision of information and advice is acceptable in MI only if the patient has given permission for this, or has confirmed a need for information. Even when approved, information and advice should only be given to a limited extent, since it interferes negatively with the patients' expressions of "change talk" [55, 160-161]. It has also been confirmed that MI is more effective than general information and advice about smoking cessation [162].

It is noteworthy that the nurses used few open questions and many closed questions (II, III). The advantage of using open questions in health care communication has been emphasised in the literature and in health care education during the last two decades [57, 160, 163-164]. The use of open questions, which is central in MI, has been shown to have a strong relationship with positive client behaviors and outcomes [61, 165] and is also associated with more complex reflections [61, 166]. Furthermore, an authoritarian, confrontational counseling approach is strongly linked to poor treatment outcomes [58, 167]. Nurses are expected to know the importance of and how to master the techniques of open questions, but our findings indicate practical difficulties in their application. The tendency to ask closed questions, and mainly give information and advice, may indicate that MI skills contrast with nurses´ traditional counseling techniques [33]. Asthma/COPD nurses have also been described as insecure in their professional role [168], which might obstruct the use of new communication methods.

After an open question is it important to listen to the answer and give reflections. Data from the videotapes showed that simple reflections were used to some extent while complex reflections were rarely used (II, III). This has also been found in studies among other health professionals with only a few days' education in MI [135, 166, 169], as was the case with the participating nurses in our study (I, II, III). The sole use

of simple reflections can result in counter-therapeutic outcomes; for instance, if nurses simply repeat and rephrase the patients' statements without a balance of other MI-components, patients may be more likely to disengage from the interaction [166]. The use of open questions and careful listening will identify the deeper meaning of patients' statements, promote trust and understanding and stimulate patients' motivation [55, 160-161]. These are important communication skills for developing empathy, the "spirit global score" and complex reflections [169].

The nurses scored low on empathy and the "Spirit global score" (II, III) - necessary tools and important components in MI to ascertain patient´s motivation, ambivalence [55] and self-efficacy [88, 170]. Empathy could identify and increase the patients' motivation and encourage the patient to move forward in the TTM-stages, from pre-contemplation and contemplation, through preparation and action towards the target-behavior [59, 80, 150, 171]. Empathy in MI is not only showing warmth, acceptance, and genuineness towards the patients' situation. It is conveying curiosity and (through active listening) supporting the patient in examining and elucidating his/her own perspective about the target behavior. Skillful emphathetic listening includes accurate reflection of what the patients say, as well as what they have experienced but not yet explicitly verbalized (complex reflections) [55]. Empathy is important in health care communication but is difficult to convey, and it is notable that the analysis of the videorecording did not judge the non-verbal communication e.g. body language such as eye contact and the smile that is so significant in empathetic communication. However, studies have shown that empathy has a positive connection to outcomes, such as life style changes [163, 172-173].

It is not possible to identify the patients' current level of readiness to change smoking behavior, e.g. in which stage of TTM, when the patients` talk is mostly neutral with a "Sure" or "OK" answer (III). The category Follow/neutral does not reflect a readiness for change, which has been proposed as an important factor in predicting client outcomes [174]. In other studies of behavior change communication, Follow/Neutral was also more frequent than the other categories [63, 65, 175]. On the other hand, patients who merely follow and are neutral towards the nurses´ claims could be regarded as behaving normally, because their intentions are to be polite and to adhere to what they think the nurse expects. Even so, it is likely to be an effect of the nurses providing a lot of information, asking mainly closed questions and exhibiting an MI non-adherent behavior, which the results in our study show (I, II, III).

6.1.1.1 Implementation

Behavior change communication is a complex skill which, in order to be successful, requires practice, feedback and coaching over time, indicating that a few days' training in MI is insufficient [47, 54, 135, 166, 176-177]. Two of these studies show that MI is difficult to learn; the Evaluation Methods for Motivational Enhancement Education (EMMEE) compared motivated, high educated counselors, who were randomized into groups with different levels of interventions. The result showed a very small improvement in the group that got the most extensive and qualified training [176]. The other study showed that there was no difference between those who only had workshop training compared with those practitioners who had performed a more extensive training with four occasions including supervision and analyses of taped consultations [135]. It has also been shown that the effects of

professionals' MI education are strongest immediately after training, diminishing greatly over time [78, 178].

It is well known that patients have difficulties in changing deeply rooted unhealthy behaviors and, unquestionably, even health care professionals have difficulties in changing their behavior such as their style of communication and interaction [33]. As a consequence of the difficulties for nurses in attaining proficiency in behavioral change communication, there is a need for more knowledge on how to reinforce and improve communication skills among nurses and other professionals in primary health care. In one study of videotaped consultations, general practitioners rarely used the recommended effective smoking cessation techniques [179]. General practitioners have also reported a lack of knowledge and skills as constituting a barrier in discussing smoking cessation with patients [180]. Analyses of video- or audio-taped consultations supervised with or without a structured coding instrument, are useful teaching methods in communication skills [132, 137, 181]. It must be stressed that supervision based on self-reporting should be avoided, as it often tends to be more optimistic and less related to performance measures [51, 69, 182]. However, health care professionals tend not to appreciate negative feedback from a supervisor even if criticism is delivered objectively and for good reasons. Negative feedback can arouse a feeling of discomfort which could counteract any benefit to improved communication skills [183-184]. Participants in MI training accepted the feedback more readily when they were involved in a plan for how to realize the feedback [184].

6.2 SELF-MANAGEMENT

The results from the intervention (IV) showed that those patients who received individually tailored self-management education and smoking cessation increased their disease-specific QoL. Patients' symptoms such as cough, phlegm, dyspnea and even the respiratory influence on daily activities decreased. Dyspnea is often the symptom that affects daily life most and is therefore the major determinant of health status [99]. The patient's ability to influence and cope with dyspnea, cough and phlegm by using medications and coughing and breathing techniques is therefore crucial for patients' perceived QoL. In order to infuse confidence and to be able to tailor care to patients' specific needs it is of importance that the nurse has disease-specific knowledge in COPD as well as knowledge in behavior change communication. Otherwise it is difficult to assess and give patients relevant education and to establish a trustful relationship. This is supported in theories of communication as in the empowerment concept where it is valuable for nurse and patients to communicate and share knowledge. The complexity of the patients' situations is emphasized as well as the need for communication that includes both a medical and a psychosocial perspective. [39]. An outcome in this concept is that the patient should overcome a barrier to change a particular behavior and when this succeeds it leads to increased self-efficacy. It is furthermore supported in studies that patients with COPD may benefit considerably from knowledge on how to handle pharmacological treatment, dyspnoea and exacerbations [125, 185-186].

It has been shown that only 50% of COPD exacerbations are reported to their physician [187]. This number of unrecorded exacerbations supports the assumption that COPD patients may have an underlying feeling of shame [105] caused by the awareness that COPD is a self-inflicted disease associated with smoking [106]. This strengthens the view that COPD patients, among other patients with chronic diseases, need support and knowledge to enhance their awareness on when to seek care. Patients can live a life that is more health-promoting by structuring their daily activities to improve physical performance, decrease dyspnoea and enhance QoL [188]. These were the goals and results of the intervention program (IV). Studies provide evidence that self-management education of patients improved their compliance and responsibility for disease management [123, 189]. Probable causes were increased self-efficacy, recognition of symptoms that are characteristic for an exacerbation and awareness of the importance of seeking care in time (IV).

The findings that the nurses did not communicate feelings of guilt and shame and that almost no time was spent on patients' ideas, fears and continuing problems are notable as all the nurses were experienced in COPD care (I). These emotional aspects are of importance in supporting self-management. Worries and fears can occupy the patients´ thoughts and block their attention to communication about self-management and/or smoking cessation. Patients with COPD are at high risk of insufficient treatment of mental health problems associated with a high level of depression and anxiety [190]. The patients' fears could also be connected to the spirometry, their worries that lung function is impaired and that they might have acquired COPD. Simultaneously, the nurses may have avoided asking about patients' fears, worries, and anxiety because they were not prepared to handle such emotional feelings. However, it has been shown that behavioral communication in the form of Cognitive Behavioral Therapy or COPD education can lead to sustainable improvements in QoL for patients with COPD who suffer from depression or anxiety [191]. It is further known that rehabilitation programmes relieve dyspnea and fatigue, improve emotional function and enhance COPD patients' sense of control over their condition [143]. However, educational programs such as the one used in the intervention (IV) need to be adapted to each patient's individual needs. If nurses follow a program merely as a checklist, going through it may lead to a stereotype consultation, not focusing on the patient's requirements.

The effects of nurse-led self-management interventions have been questioned. In a review of studies on nurse-led COPD clinics there were no significant differences in comparison with conventional care. The studies in the review included hospital care, out-patient clinics and community-based home care led by nurses, and the variables studied included health-related quality of life (HRQoL), mental health, disability, respiratory function and numbers of hospital admissions In one of the studies with a more structured programme a decreased number of hospital admissions was found amongst patients in the intervention group [192]. Because of the scant description of the interventions included in the review, it is possible that the outcomes were attributed to a lack of structure of the intervention program.

6.3 INDIVIDUAL TREATMENT PLAN

One explanation of the improved QoL in the intervention group (IV) is that self-management education and smoking cessation were combined with an individual written treatment plan produced in collaboration between nurse, patient and physician.

Another factor contributing to the positive outcome, also included in the treatment plan, may be that the care in the intervention group involved collaboration with the physiotherapist, dietician, medical social worker and occupational therapist, when needed. An example of co-operation could be the contribution of a physiotherapist in patients' physical exercise, breathing and coughing technique, relaxation and pelvic muscle exercise improving activity tolerance [193]. Dietary counseling is another area of co-operation that can counteract weight loss as well as promoting well-being and reducing dyspnea. [101-102]. Dietary counseling does not only cover physiological matters, but also complex psycho-social matters [194]. Normal co-operation with the physician led to the adjustment of pharmacological treatment in the intervention group to a higher extent than in the control group, possibly reducing respiratory symptoms in a positive way (IV).

In a review of five studies including 574 persons with COPD, it was concluded that treatment plans result in increased ability of patients to recognise and react appropriately to exacerbations. These treatment plans should be combined with multifaceted self-management programs [123]. Another study confirmed that individual self-management education, in combination with a written individual treatment plan, resulted in decreased hospital re-admission, unplanned physician visits, sick leave and nocturnal symptoms in patients with COPD [121]. A written treatment plan produced together with the patient, summing up the consultation, may be a means of clarifying shared understanding of responsibilities [7, 122, 195]. It could also be a helpful support for patients to have a copy as a reference when symptoms and other difficulties appear in daily life (IV). A treatment plan is the basis for the quality of the concluding phase of the consultation and for effective follow-up visits. A treatment plan could support focus on the target behavior, for example the issue in self-management education or the smoking cessation. This is in accordance with the MI communication method, where it is important to influence and to focus the communication on the TBC. It is notable that almost none of the consultations in the first study were finalized with an oral or written treatment plan summing up problems, actions and responsibilities. This was an unexpected finding because most of the patients were smokers with COPD, and should, therefore, have had follow up appointments with the COPD-nurse (I).

The lack of a treatment plan might also explain the lack of educational interventions (I), indicating that decisions about teaching were inadequately directed by clear goals or tailored programs [196]. Another consequence of the non-existent treatment plans could be the lack of differences found in nurses' (MITI) and patients' (CLAMI) communication between the first and third consultation (II, III). The patients in the third consultation had met the nurses twice before in consultations planned for one hour and yet there was neither change in guidance, nor deeper talking about the patient's inner will that could have evoked the motivation to change behavior. It is hypothesized that behavior change could emerge gradually over time with a growing relation depending on successive guidance and encouragement of the patient [55]. In the third consultation the patients would have been expected to express more reason for change, more steps and commitment toward smoking cessation (III) [59] This was shown in the result from the intervention group, where steps and commitment toward behavioral changes and smoking cessation were adopted by the patients (IV).

6.4 METHODOLOGICAL CONSIDERATIONS

6.4.1 Papers I, II and III

A majority of the patients included in the studies were women (I, II, III), which reflects the current gender distribution among patients in PHC [197] . The variation of severity of COPD in the sample represents the common pattern of the disease in primary health care (I, II, III, IV). This is coherent with a study of nurse-led clinics for respiratory diagnoses, in which it was shown that the largest group of patients was those with suspected COPD [198].

6.4.1.1 Videotaping

Videotaping as a research method might influence nurses' and patients' communication (I, II, III). In this study the participating nurses were specialized and experienced in COPD care, and aware of the purpose of the study, implying that they had an interest in doing a good job, which constituted an unavoidable selection bias. However, videotaping could be seen as a strength in facilitating the collection of data on complex interaction and behavior in clinical consultations [199-200]. It has also been claimed that videotaping is an unobtrusive observational method, which causes limited disturbance to the consultation process and is therefore considered to be a valid and reliable method [201]. In line with experience from other studies, only one out of ten participants refused to take part in videotaping studies [130]. In the analysis of the smoking cessation communication (II, III) the coders did not use the videotaped material to its full extent, as they coded the verbal but not the non-verbal communication. This entails the possibility that valuable information in the non-verbal communication was missed (II, III).

6.4.1.2 Instruments

The CM (I) has been criticized for shortcomings in analyzing human interaction with such a "checklist" and the inherent loss of nuances [202]. Loss of nuances can also be a valid criticism of the judgment of the self-management issues given in the consultation. The analyzed communication according to the content in the CM did not, however, exclude any data. This indicates that the CM (supplemented with an investigational phase, an educational phase and miscellaneous, Appendix 1.) covered the actual content of the consultations and is valid for analyzing the communication at COPD-nurse clinics. This is further supported by the time identified as "miscellaneous" being limited. The evaluation of the specific content in the self-management education was particularly important because of the comprehensive educational content of the visits at nurse-led COPD clinics. The judgment of the relevance of information in the self-management education must be considered in the light of the fact that some of the included patients had neither COPD, nor were smokers and did not need the self-management education to the same extent as the COPD patients. However, the results both from the CM and from the analysis of the content in the self-management education give an important picture of communication and education during these one-hour scheduled visits.

MITI and CLAMI (II, III) have not previously been used in studies of nurses' communication in primary health care. The instruments are developed for analysis of 20-minute segments [73]. In the present study, the smoking cessation communication during a session was coded and its duration in the consultations varied greatly (range: 2 - 27 minutes). Longer dialogues about smoking yielded both more MITI and

CLAMI, and could be interpreted as a bias of data. Another limitation was that the Global score Direction (II, III), which measures the degree to which the nurses maintain appropriate focus on smoking cessation, scored 5 (highest) in all consultations, due to the fact that only the smoking cessation time was analyzed [73]. Therefore, it could have been better in the direction score to take the whole consultation into consideration. In spite of these weaknesses, the MITI (II) has been shown to be a suitable tool for measuring entry-level competence in MI, and MITI adequately measures relevant communication features such as empathy and open questions [132].

6.4.2 Paper IV

In the intervention study, a confounding factor may have been that one of the researchers (EÖE), as a nurse in the PHCC, performed the intervention. This implies that patients were in a dependent position in relation to the researcher which may have induced social desirability and thus affected the responses in a favorable direction. Moreover, patients may have been affected by the "Hawthorne" effect in the sense that they were given an individualized treatment program and felt acknowledged in their disease. The researchers are also aware of the fact that a follow-up time close to the intervention may show better results than a longer follow-up time. Some of the patients who were randomized into the control group were disappointed about this randomization, which might have affected their responses in a negative direction. However, the patients in the control group were offered the same program as the intervention group after the intervention was concluded (IV).

Most patients were recruited from the PHCC where the intervention was carried out, because of the close collaboration between the COPD nurse and physicians, a fact that may have entailed a selection bias of patients. It could be assumed that physicians were more positive and encouraged the patients to participate in the study and also that they were inclined to observe symptoms of COPD and refer patients to the nurse-led clinic more frequently. This may imply that the study population was more motivated than a general population. It seems as though the intervention *per se* did encourage increased attention and early diagnosis of these patients. Generalization from the findings must therefore be done with caution, because of the relatively small sample and the possible selection bias (IV).

6.4.3 Internal and external validity (I, II, and III)

In the first analysis of the videotaped consultations with the CM one of the researchers (EÖE) performed the analysis. The analysis with the MITI and CLAMI was performed by three independent coders at MIC- lab at The Karolinska Institute. Both the analysis with the CM, MITI, and CLAMI showed agreement in the result. For example similar results were found: few open questions were used (I, II, III); patients' concerns, fears and problems were rarely discussed (I), which could be related to the MI-spirit and Empathy global scores in the MITI (II, III); shared understanding and responsibility was rarely communicated (I), which coheres with the global score collaboration (II, III). The result of low scores of mentioned variables also cohered with the result from the CLAMI (III), in which the patients' answers were mostly neutral and did not express reason or commitment for change. This increases the credibility, reliability,

generalizability and transferability. A higher score in the communication variables by the nurse had probably influenced the results in a positive direction.

6.5 CONCLUSION

The following conclusions from the studies at nurse-led COPD clinics in this thesis could be drawn:

- Most of the consultation-time at nurse-led COPD clinics was spent on patients' medical and physical problems, on investigations such as spirometry, on information on self-management and smoking cessation and on practical suggestions and recommendations e.g. how the patients should use their medications or how to manage to stop smoking.
- The communication rarely involved patients' ideas, fears and continuing problems.
- Shared understanding and responsibility were rarely observed and the consultations were not summarized in a written treatment-plan.
- Within the MI context, the nurses seldom showed empathy, rarely collaborated with patients, or supported the patients' autonomy.
- The nurses provided a lot of information, posed closed questions and made simple reflections, whilst open questions and complex reflections were seldom used.
- Patients' utterances in the smoking cessation communication mostly followed or were neutral towards what the nurses had said, with a "Sure" or "OK".
- Patients' desires, abilities and needs for or against smoking were expressed only to a small degree and patients rarely talked about concrete steps towards or made a commitment to stop smoking.
- The number of patients who stopped smoking increased, and patients' knowledge about the disease and their QoL was improved, by structured and tailored self-management education and smoking cessation, in collaboration between patient, nurse and physician and (when needed) a physiotherapist, dietician, occupational therapist or medical social worker.
- Conventional COPD care (when the patient with COPD turns to the PHC in an emergency or when summoned to an appointment with a physician), compared to a nurse-led COPD-clinic intervention, had no effect on patients' QoL and smoking habits.

6.6 IMPLICATIONS FOR PRACTICE

Smoking cessation and self-management education are important features at nurse-led clinics for patients with COPD. The results on shared understanding and responsibility, treatment plans, how to talk about patients' concerns, fear and worries and behavioral change communication can all be used as a basis for reflection and discussion among nurses, physicians and managers on how to develop consultations with patients with chronic diseases. A first step towards improved smoking cessation and self-management education could be a written treatment-plan tailored to each patient's specific needs. A written treatment plan can increase collaboration, shared understanding, responsibility and patients' control of their own disease, and facilitate health-promoting self-management.

At these clinics, smoking cessation and self-management education are the most important "treatment tools". In order to practice more interactive communication, training in behavioral change communication has to be increased and improved in nursing education, both at a basic and advanced level, and in continuing education in clinical practice. Education and continuous education has to focus on how to talk with patients about psychosocial disabilities and on the importance of discussing the patient's ideas, fear, worries and problems. The education and training also has to be focused on teaching techniques for active listening, open questions and complex reflections. PHCC, and other clinics in healthcare that want to increase their professional competence in communication, have to provide time and space for education, continuing education and repeated training in communication. For example, in order to improve and maintain already acquired skills in communication and to minimize feedback resistance, coaching-groups including a supervisor can be used. Here the participants analyze each other's videotaped consultations during discussions, and the pedagogical base is learning-by-doing.

The communication between nurse and patient could also be improved if the patients were better prepared before the consultations. The patient could, by e-mailed questions, be encouraged to consider their ambivalence towards smoking, positive and negative factors, their motivation to quit smoking and their beliefs about their capability for smoking cessation. These questions could then be discussed during the consultation.

Consequently there is a need to acquire more knowledge about important factors in the consultation between nurses and patients. Nurses working with people with a chronic disease, such as COPD, need more education in behavioral change communication. Smoking cessation and self-management education for people with chronic diseases is and will be a challenge in today's and tomorrow's primary health care.

6.7 FUTURE RESEARCH

Specialised nurse-led clinics in PHC will have a pivotal role in caring for the increasing number of patients with chronic diseases, including COPD, in the future. It is therefore important to continue research to further develop our knowledge about the most effective methods for the treatment and care of such patients. An issue for future research is the investigation of the effects on smoking cessation and HRQoL of self-management education and smoking cessation, delivered by nurses that have been trained and reached an approved level in behavioral change communication.

7 SUMMARY IN SWEDISH

7.1 BAKGRUND

Livsstilsrelaterad ohälsa utgör idag en stor belastning för hälso- och sjukvården liksom för samhället i stort. Sjukligheten i Europa orsakas till mer än 50% av ohälsosamma levnadsvanor som t.ex. fysisk inaktivitet, dåliga kostvanor, tobaksanvändning, alkoholkonsumtion och stress. I hälso- och sjukvårdslagen och i vårdprogram för olika kroniska sjukdomar poängteras vikten av rådgivning och stöd till patienter som av hälsoskäl behöver genomföra en livsstilsförändring. Världshälsoorganisationens (WHO) Europaregion antog år 2002 Warszawadeklarationen med riktlinjer för ett rökfritt Europa. I deklarationen är det fastställt att rökavvänjning är en evidensbaserad och viktig åtgärd i arbetet mot tobak och att det är varje nations ansvar är att utbilda hälso- och sjukvårdspersonal i tobaksavvänjning.

God kommunikation är grunden i egenvårdsundervisning och i rökslutarstöd. Egenvårdsundervisning som är skräddarsydd utifrån patientens behov ökar patientens delaktighet i vård och behandling. Det har visat sig att det inte är tillräckligt att enbart ge hälsoinformation till patienter som behöver ändra sina levnadsvanor för att få en bättre hälsa. För att stödja patienter till beteendeförändring behövs det en mer strukturerad form av kommunikation, exempelvis genom tillämpning av specifika teoretiska och konkreta modeller. En god kommunikation ska ha respekt för patientens integritet och inkludera; känslomässigt stöd, information, patientutbildning, motiverande samtal, egenvård med hänsyn till patientens problem och förutsättningar, samordning av vården, delat ansvar för egenvård, samt behandling och dokumentation.

Sjuksköterskor kommer i framtiden i större utsträckning arbeta med patienter som har kroniska sjukdomar. Omfattningen och komplexiteten av dessa sjukdomar kommer att innebära behov av nya kunskaper, färdigheter, förändrad organisation och nya professionella roller. Sett utifrån detta perspektiv står sjuksköterskeledda mottagningar för patienter med kroniska sjukdomar inför nya utmaningar ex diabetes, hjärtsvikt, astma och kroniskt obstruktiv lungsjukdom (KOL). Det kommer att behövas en kombination av olika metoder och behandlingar för att på bästa sätt stödja dessa patienter till, ur ett hälsoperspektiv, nödvändiga livsstilsförändringar.

7.2 KOMMUNIKATIONSMODELLER OCH METODER

Modellerna och metoderna nedan är både teoretiska och praktiska. De ger oss kunskap om vad som vi bör tänka på, hur vi ska förhålla oss samt hur vi praktiskt kan gå till väga när vi samtalar med patienter om beteendeförändringar Dessa modeller/metoder kan användas var för sig men även kombineras för att åstadkomma bästa möjliga resultat utifrån patienternas behov.

Empowerment utgår från att en välutbildad patient är en förutsättning för delaktighet i samarbetet vad gäller t.ex.egenvårdundervisning. Empowerment beskrivs som ett professionellt *förhållningssätt* där patienten ges möjlighet till medbestämmande, engagemang och kontroll och som underlättar patientens lärande och reflektion över vilka attityder, beteenden och åtgärder som gagnar en hälsofrämjande egenvård.

Motiverande samtal, på engelska Motivational Interviewing (MI) har blivit en allt vanligare metod i hälso- och sjukvårdens arbete för att stödja och påverka människor att förändra sina levnadsvanor. Behandlaren har ett ledande förhållningssätt för att stödja patienten till att göra förändringar utifrån sin inre motivation, genom att ställa öppna frågor, lyssna, reflektera, bekräfta och summera vad patienten säger. Målet är att försöka göra patienten mer medveten om riskbeteende, problem som kan uppstå, och om vilka konsekvenser och risker som beteendet för med sig. MI utgår från fyra principer: att uttrycka empati, utveckla diskrepans, dvs. att uppmärksamma brist på överensstämmelse mellan aktuellt beteende och egna värderingar, undvika att argumentera och stödja patientens tilltro till sin förmåga att genomföra en önskad förändring. Strategin är att skapa nya tankebanor om beteendet, och slutligen föreställa sig vad som går att vinna på förändring.

Transtheoretical model (TTM) of change beskriver vilka faser en människa genomgår i försök att genomgöra en avsiktlig beteendeförändring. Faserna utgör logiska steg i förändringsprocessen som är praktiskt överförbara till det kliniska arbetet i kommunikation om beteendeförändring. Modellen beskriver fem faser i förändringsprocessen: före begrundan (omedveten om problemet), begrundan (medveten om problemet), beslut och förberedelse (välja väg, fatta beslut och förbereda sig genom att göra en plan), samt handling (motivationen ska omsättas i handling) och stabilisering (livet kan hanteras utan fokus på problemet). Varje fas innebär psykologiska utmaningar som måste hanteras för att personen ska komma vidare i processen och flytta sig framåt genom faserna. Modellen gör det möjligt att stanna upp eller återgår till en tidigare fas i de fall där förändringen inte lyckas att genomföras. Det har visat sig att rökare i medeltal går igenom de olika stegen 4 gånger innan de lyckas sluta att röka.

Self-efficacy handlar om att ta reda på patientens tilltro till sin egen förmåga; att klara av att ändra ett specifikt beteende i en specifik situation. Beteendeförändringen delas in i små steg, och individiden har själv kontrollen över och på vilket sätt förändringen ska ske.

7.3 KRONISKT OBSTRUKTIV LUNGSJUKDOM

KOL är den fjärde vanligaste dödsorsaken i världen och ökar nu även i tredje världen. WHO beräknar att sjukdomen år 2020 kommer att vara världens tredje vanligaste dödsorsak. Kostnaderna för KOL i Sverige är omkring nio miljarder kronor per år och är relaterad till sjukdomens svårighetsgrad; svår KOL (stadium 4) kostar samhället tre gånger mer än KOL i stadium 3 och tio gånger mer än lindrig KOL (stadium 2). Svenska populationsbaserade studier tyder på att cirka åtta procent av Sveriges befolkning över 50 år har KOL och att minst 25 % av rökarna drabbas, med ökad risk ju äldre man blir. Av de rökare som uppnår 75 års ålder beräknas cirka hälften ha KOL.

KOL är en kronisk, invalidiserande sjukdom med smygande sjukdomsförlopp, patienten försämras långsamt med ökande andnöd. Symtom är kronisk hosta, slembildning, pip i bröstet och andnöd. Vid avancerad sjukdom förekommer ofta andningsinvaliditet med mycket svåra symtom och dålig livskvalitet. Svårt sjuka personer med KOL är ofta beroende av kontinuerlig syrgasbehandling och har ofta symtom från andra organ än lungorna, (t ex hjärtsvikt, osteoporos muskelsvaghet,

kognitiv dysfunktion) de lider nästan alltid en intensiv trötthet och har dessutom mycket ofta av svår depression.

Personer med KOL har ofta en omfattande och ibland svårhanterlig medicinering och sjukdomen innebär risk för snabba försämringar med behov av sjukhusvård. Vid KOL påverkas individens fysiska, sociala och emotionella funktioner. Fysisk träning, andnings- och hostteknik, avspänningsövningar och bäckenbottenträning förbättrar prestationsförmåga och livskvalitet. Genom att kartlägga patientens dagliga rutiner kan patienten ges stöd att planera sin vardag utifrån sina symtom. Kostrådgivning och koståtgärder kan vända en negativ viktutveckling och medföra ökat välbefinnande och minskad andnöd. Program för rehabilitering resulterar ofta i förbättrad prestationsförmåga, mindre andnöd och förbättrad livskvalitet.

Eftersom tobaksrökning är den viktigaste riskfaktorn för utveckling av KOL är behandlingen av tobaksberoendet en prioriterad åtgärd; ju tidigare rökstopp desto bättre prognos och gynnsammare sjukdomsförlopp. Rådgivning har visat sig ha effekter på rökstopp där professionella samtal med omfattande rådgivning och återbesök visat sig vara mest effektivt. Studier visar att rökavvänjning vid KOL har ett bättre resultat när man kombinerar farmakologisk behandling med psykosocial intervention jämfört med enbart psykosocial behandling eller ingen behandling alls. Det har även visats att upprepade spirometrier tillsammans med rökslutarstöd leder till att fler individer med KOL som röker slutar att röka. Rökslutarstöd i grupp har visat sig vara lika effektivt som intensiv individuell rådgivning (med beteendeförändringskommunikation).

7.4 PRIMÄRVÅRDENS KOL-MOTTAGNINGAR

Primärvårdens roll är att tidigt upptäcka, diagnostisera, behandla och följa upp patienter med KOL samt erbjuda patientundervisning och behandling mot tobaksberoende. Målet är att minska symtom, förbättra livskvalitet och öka den fysiska och sociala aktiviteten. I Socialstyrelsens riktlinjer från 2004 anges specifika mottagningar som en kvalitetsindikator för omhändertagande av KOL-patienter i primärvården. Utifrån dessa riktlinjer har det utarbetats kriterier. En godkänd astma/KOL mottagning ska enligt kriterierna innehålla: strukturerade utredningar, undersökningar såsom, spirometri, pulsoximetri, peak expiratory flow (PEF), PEF-kurva, patientundervisning, rökavvänjning, och regelbundna uppföljningsbesök. Rekommenderad tid för ett första besök är en timme.

Åttiosju procent av Sveriges vårdcentraler har en astma/KOL sjuksköterska och på dessa vårdcentraler har patienter med KOL färre akuta försämringar jämfört med vårdcentraler där det inte finns en astma/KOL-sjuksköterska. I en rapport där KOL-vården i region Mellansverige har kartlagts, utifrån Socialstyrelsens riktlinjer, har det framkommit att det är önskvärt med ett ökat rökslutarstöd, ökad rehabilitering och mer tid avsatt för primärvårdens astma/KOL mottagningar.

7.5 PROBLEMFORMULERING

Kommunikation i samband med egenvårdsundervisning och rökslutarstöd innebär en stor utmaning. Majoriteten av de som drabbats av KOL mår dåligt både fysiskt och psykiskt och många av dessa patienter känner rädsla, oro, skuld och skam, vilket gör kommunikationen med dessa patienter till en ännu större utmaning. Det har också visat sig att även om vårdpersonal har fått utbildning och träning i kommunikation så är det svårt för dem att ändra ett invant kommunikationsbeteende. Problemet har varit att ändra ett auktoritärt förhållningssätt där vårdaren är expert till ett mer stödjande förhållningssätt som bygger på empowerment. Sjuksköterskor som arbetar med dessa patienter behöver sjukdomsspecifik kunskap och medicinsk kunskap men även kunskap i någon patientcentrerad, teoribaserad kommunikationsmodell för att på bästa sett stödja patienterna till egenvård och rökstopp.

Sammanfattningsvis kan konstateras att det finns ett behov av mer kunskap i hur kommunikationen som redskap används i egenvårdsundervisning och i rökslutarstöd. Detta för att medvetandegöra och reflektera över komplexiteten vad gäller vården av patienter med KOL. Sådan kunskap kan utgöra en grund för utvecklandet av bättre rökslutarstöd och egenvårdsundervisning för patienter med kroniska sjukdomar och för patienter med KOL.

7.5.1 Syfte

Avhandlingens övergripande syfte var att undersöka kommunikationen mellan patient och sjuksköterska på sjuksköterskeledd KOL-mottagning i primärvård vad gäller patienternas beteendeförändring med fokus på rökslutarstöd och egenvårds-undervisning.

7.5.2 Design

Studierna har genomförts med observation, prospektiv observation och experimentell design på KOL-sjuksköterskemottagningar i primärvård.

7.6 METOD

För att utforska och beskriva strukturen, innehållet och kommunikationen i egenvårdsundervisningen och i rökslutarstödet på KOL-mottagningar har 30 nybesök/patienter fördelade på sju sjuksköterskor vid olika vårdcentraler videofilmats (delarbete I). För att utforska och beskriva rökslutarsamtalet har tretton rökande patienter fördelade på sex sjuksköterskor vid olika vårdcentraler under ett nybesök och under ett tredje återbesöket, totalt 26 besök videofilmats (delarbete II och III). För att undersöka effekten av strukturerad egenvårdsundervisning har 52 patienter med diagnosen KOL randomiserats till antingen interventionsgrupp (n=26) eller kontrollgrupp (n=26). Båda grupperna erhöll standardvård. Interventionsgruppen fick därutöver två besök till en distriktssköterska specialiserad på KOL (delarbete IV).

Strukturen och innehållet i besöken analyserades med Pendelton's konsultationskarta, Consulting Map (CM). Sjuksköterskornas egenvårdsundervisning bedömdes utifrån innehållet i kommunikationen: om viktig och relevant information och egenvårdsundervisning gavs. Det gjordes även en bedömning av hur undersökningarna (spirometri, pulsoximetri, peak exploratory flow (PEF)

genomfördes (delarbete I). Rökslutarsamtalet analyserades utifrån två kodningsmanualer som bedömer kvaliteten i kommunikationen; Motivational Interviewing Treatment Integrity (MITI) kodningsmanual version 3.0 och Client Language Assessment in Motivational Interviewing (CLAMI) kodningsmanual (delarbete II och III). Effekten av strukturerad egenvårdsundervisning utvärderades med en enkät med frågor om demografiska data och rökstatus och med ett livskvalitetsinstrument med frågor om hur andningsbesvären påverkar patientens livskvalitet, St. George's Respiratory Questionnaire (SGRQ). Båda grupperna svarade på enkäterna vid det första besöket och vid det sista besöket efter tre till fem månader (delarbete IV).

7.7 RESULTAT

7.7.1 Delarbete I

Den genomsnittliga konsultationstiden var 37:53 minuter. Anamnesen (patienternas berättelse hur de hanterar och upplever sin sjukdom i det dagliga livet) handlade till största delen om medicinska och fysiska problem och i liten utsträckning om patienternas oro, rädsla eller föreställning om KOL-sjukdomen. Besöken planerades inte tillsammans med patienten och inget av besöken utmynnade i en behandlingsplan. Undervisningen i egenvård och rökslutarstöd utfördes till största delen genom att patienternas fick information. Två av 30 konsultationerna avslutades med delat samförstånd mellan sjuksköterska och patient. I den sjukdomsspecifika undervisningen fick hälften av patienterna utbildning i anatomi och patofysiologi, farmakologisk behandling och inhalationsteknik. Två tredjedelar fick undervisning om vikten av fysisk aktivitet, en patient fick undervisning i host- och andningsteknik. Ingen av patienterna blev undervisade om hur de skulle kunna hantera akuta försämringar och ingen fick psykosocial rådgivning. Arton av de 22 rökande patienterna fick rökslutarstöd.

7.7.2 Delarbete II och III

Fördelning av rökslutarsamtalstiden mellan sjuksköterska och patient visade att i en tredjedel av konsultationerna (n=26) pratade sjuksköterskan och patienten lika mycket och i två tredjedelar pratade sjuksköterskan mer än patienten. Sjuksköterskornas kommunikation var till en liten del samarbetsfrämjande, autonomistödjande och framlockande av patientens argument till rökstopp. I samtalet om rökavvänjning gav sjuksköterskorna mycket information (42%), använde mer slutna än öppna frågor, gjorde fler enkla än komplexa reflektioner och hade fler uttalanden oförenliga med MI än förenliga med MI. I samtalet om rökavvänjning var patienternas uttalanden till största del varken för eller emot rökstopp och kodade i kategorin Följa/Neutral. Patienterna diskuterade även orsak till att göra en förändring såsom önskan, förmåga och behov men det var inga uttalanden hos patienterna som att ta steg mot eller åtagande att genomföra förändringen Det var inga skillnader i resultat varken vad gällde MITI eller CLAMI mellan den första och tredje konsultationen.

7.7.3 Delarbete IV

Det var en statistiskt säkerställd skillnad i interventionsgruppen gällande rökstopp, livskvalitet och upplevda kunskaper om KOL. Patienterna i interventionsgruppen

hade fått minskade andningsbesvär, hade ökat sin fysiska aktivitet och hade fått bättre psykosocial hälsa efter interventionen. Interventionen bestod av två besök till KOL-sjuksköterska med fokus på egenvårdsutbildning och rökslutarstöd. Patienterna i kontrollgruppen uppvisade ingen förändring. I interventionsgruppen hade 6 av sexton rökande patienter slutat röka medan ingen patient hade slutat av de 14 rökande patienterna i kontrollgruppen.

7.8 SLUTSATSER

Kommunikationen på KOL-sjuksköterskemottagning i primärvård var fokuserad på patientens fysiska och medicinska besvär och handlade till en mycket liten del om patienternas rädsla, oro, funderingar och problem. Delad förståelse och ansvar mellan sjuksköterska och patient förekom i mycket liten omfattning och ingen av konsultationerna avslutades med att en behandlingsplan upprättades. Rökavvänjningen var till liten del samarbetsfrämjande, autonomistödjande och framlockande av patientens argument till rökstopp. Sjuksköterskorna gav mycket information, ställde slutna frågor och återkopplade med enkla reflektioner. Det var sällsynt att sjuksköterskan ställde öppna frågor och uttryckte komplexa reflektioner i dialogen med patienten. Patienternas uttalanden i rökslutarsamtalen var till liten del fokuserat på orsak till att vilja sluta röka och att ta steg eller åtagande i riktning mot ett rökstopp. Resultatet visade även att strukturerat, individuellt anpassat rökslutarstöd och egenvårdsundervisning på KOL-sjuksköterskemottagning i primärvård, ökade patienternas sjukdomskunskap, livskvalitet och antal patienter som slutade att röka.

Rökslutarstöd och egenvårdsundervisning är viktiga delar i sjuksköterskeledda mottagningar för personer med kroniska sjukdomar exempelvis på KOL-sjuksköterskemottagningar i primärvård. Resultatet kan användas av sjuksköterskor, läkare och arbetsledning för att reflektera och diskutera utifrån hur egenvårdsundervisning och rökslutarstöd kan utvecklas och därmed förbättras på dessa mottagningar. Ett första steg mot en förbättrad egenvårdsundervisning med ökat samarbete och delat ansvar skulle kunna vara att regelmässigt upprätta individualiserade skriftliga behandlingsplaner tillsammans med varje patient.

Sjuksköterskor behöver ökad utbildning och träning i kommunikation för att bättre kunna stödja patienter med kroniska sjukdomar såsom KOL till att genomföra livsstilsförändringar som leder till bättre hälsa. Ökad utbildning i kommunikation behövs i sjuksköterskeutbildningen både på grund- och avancerad nivå samt fortlöpande i det kliniska arbetet. Vårdcentraler och kliniker inom slutenvård som önskar öka personalen kommunikationskompetens måste ge tid och utrymme för utbildning fortbildning och regelbunden träning. Utbildning och träning i kommunikation behöver fokusera på öppna frågor och reflektivt lyssnande för att bättre kunna locka fram och förstå patientens motivation. Exempel på regelbunden fortbildning och träning kan vara att personalen videoinspelar egna konsultationer som de därefter analysera tillsammans med handledare i kommunikationsteknik.

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9 APPENDIX

Appendix 1. Description of the concepts in the Consultation Map

Phase 1	**Includes the reason for the patient's consultation.**
A. History	The patient reports on a normal day and about how life is affected by respiratory symptoms such as breathlessness, cough, phlegm, medication for COPD, change for the worse, fatigue, concentration difficulties, reduction in weight, physical activity/exercise.
B. Aetiology	Smoking history (how much, how long), heredity (for instance, lack of alfa 1 antitrypsin), environmental influence (asbestos, dust, air pollution), other allergies, overweight.
C. Patient's Ideas	What the patient believes about e.g. the disease and symptoms. What is the nature of the problem, causal relationship, significant and possible results not corresponding to medical knowledge?
D. Patient's Fears	Anxiety, concern.
E. Continuing problems	The influence of the disease on work, leisure time and relations to other people, for instance being on the sick list, social isolation.
F. Other problems	Problems lacking relevance for the COPD disease, for instance discussion about other diseases, other medication.
G. Risk factors	Health problems, for instance brittle bone disease, heart failure, lung cancer.
Phase 2	**Covers investigations**.
H. Investigations	Investigation and accompanying information on; height, weight, spirometry and peak exploratory flow (PEF) before /after broncho-dilating medication, pulsoximetry before /after exertion.
Phase 3	**Includes education and smoking cessation in different ways.**
I. Education level 1	The patient is passive while the nurse informs and counsels without any particular agreement with the patient.
J. Education level 2	The patient is active and asks questions. The nurse asks open-ended questions and checks that the patient has understood the education by asking reciprocal questions, thus involving the patient in the self-managed education.
K. Education level 3	As level 2 but with even more consideration for the patient's needs and wishes. The nurse checks with the patient what knowledge is needed and thereafter makes suggestions. The patient can then choose what areas of education and counseling to take into consideration.
L. Support patient for smoking cessation level 1	The nurse informs about the detrimental effects of smoking and the patient answers closed questions asked by the nurse.
M. Support patient for smoking cessation level 2	The nurse uses motivational dialogue, with open-ended questions that make the patients think actively about their own attitudes and decisions.
Phase 4	**The conclusion of the consultation.**
N. Shared understanding	Choosing appropriate action for each problem together with the patient and achieving a shared understanding of the problems.
O. Action taken	Suggestions, recommendations – for instance changes in medication, more exercise, referral - for instance to a dietician, occupational therapist, physiotherapist, lung specialist. The patient is requested to provide a PEF-curve, using a prescribed PEF meter. Alternatively, a decision to do nothing at all.
P. Shared responsibility	Encouraging the patient to accept appropriate responsibility. Summing up problems, actions and responsibility.
Q. Miscellaneous	Disturbances such as a knock on the door, other health care professionals asking questions, cell phone ringing, the nurse leaving the room.

Appendix 2. Description of the concepts in self-management education and their division into categories [15, 128]

Content of self-management education in consultations	**Carried out after the nurse's judgment of relevance**	**Carried out to some extent**	**Not carried out even if it was relevant**
Spirometry	The spirometry investigation is correctly performed with usable results and the outcome is explained to the patient.	The spirometry and/or the teaching are partly incorrect or some element is not involved.	The spirometry is not carried out.
Pulsoximetry	Investigation of oxygen saturation, pulsoximetry, before and after exertion.	Investigation only while the patient is at rest.	No investigation at all even if it had been relevant.
Patophysiology	Description of the anatomy and physiology of the breathing passages, and the effects of COPD.	The teaching is partly incorrect or some element is not involved.	Relevant information is not mentioned at all.
Pharmacological treatment and inhalation technique	Optimization of pharmacological treatment and control of inhalation technique. Explanation to patients of when, how, and why they should take their medications.	The teaching is partly incorrect or some element is not involved.	Relevant information is not mentioned at all.
Acute exacerbations	Instructions on how patients should manage on acute exacerbations.	Mentioned but not explained to the patient how to react and handle.	Relevant information is not mentioned at all.
Coughing technique	Instructions on coughing technique to prevent infection and exacerbation.	The teaching is partly incorrect or some element is not involved.	Relevant information is not mentioned at all.
Breathing technique	Assessment and instruction of breathing technique. Patients were instructed how to cope with respiratory problems, especially in exertion.	Mentioned but without instruction or checks.	Relevant information is not mentioned at all.
Motivational dialogue about smoking cessation	Motivational dialogue based on open questions to help patients reflect on their smoking habits and empower patients to quit smoking.	The dialogue is not motivational and no (or only a few) open-ended questions are asked, the nurse does not follow up the questions. The nurse informs about the detrimental effects of smoking.	Smoking cessation is not mentioned to smokers.
Infection prevention	Counseling for influenza vaccination and/or pneumo-vaccination.	Relevant information is not mentioned at all.	Relevant information is not mentioned at all.
Physical activity	Dialogue on physical activity and exercise with suitable suggestion from the patients or/and from the nurse.	Asked the patient but not followed up the answer, if the patient did exercise or not.	Relevant information is not mentioned at all.
Psycho-social counseling	Psycho-social counseling and support to some extent.	Relevant dialogue is not mentioned at all.	Relevant dialogue is not mentioned at all.
Dietary counseling	Dietary counseling; intensified to patients with severe COPD with recipe on nutritional supplements and referral to dietician.	The teaching is partly incorrect or used only to some small extend.	Relevant information is not mentioned at all.
Individual treatment plan in writing.	Individual written treatment plan in collaboration with the patient e.g. including how patients should adjust medication on exacerbation and when to consult the physician.	Orally agreed treatment plan.	No treatment plan at all even if it was relevant.

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