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Summary

Background: Chronic obstructive pulmonary disease (COPD) is the only disease whose age-adjusted mortality continues to increase. The disease trajectory for the patients involves years of chronic illness, interrupted with periods of exacerbation and acute ventilator failure. An acute exacerbation is life-threatening and two-year survival rate for hypercapnic respiratory failure following noninvasive ventilation is about 50 %. Acute exacerbation often requires decisions about whether or not to initiate noninvasive ventilation and mechanical ventilation. Limiting such treatment for patients with serious deterioration of chronic obstructive pulmonary disease is closely associated with end-of-life decision-making.

Aim: The overall aim of this thesis was to explore the physicians' and nurses' considerations and values in the decision-making processes regarding noninvasive ventilation and mechanical ventilation for older patients with late-stage COPD. Moreover, the aim was to elucidate the patients' illness experiences and elucidate their involvement in decision-making regarding noninvasive ventilation and mechanical ventilation.

Methods: This thesis has employed a qualitative research design, using a hermeneutic phenomenological methodological approach. The empirical material is based on both focus-group interviews conducted with 14 physicians (four groups) and 26 nurses (six groups) and individual interviews conducted with 12 patients with late-stage COPD. The healthcare personnel worked bedside in either intensive-or respiratory wards. The participating patients were all in the late stages of the disease (GOLD III-IV). The discussions in the focus group interviews focused on the health care personnel's rationales, values and considerations in the decision-making process regarding noninvasive ventilation and mechanical ventilation for these older patients. In the individual interviews the discussions focus on the patients' illness experiences and involvement in the decision-making process. A pilot study was conducted prior to the focus group studies.

Findings: The findings of this study are presented in three papers, which highlighted complementary aspects of the same phenomenon, namely the decision-making processes regarding ventilation support for patients with late-stage COPD. The principle findings

running through all three papers are that patients with late-stage COPD are rarely included in decision-making about the possible treatment options at the end of their lives.

In Study I, the findings reveal that the decision-making process is medically and ethically challenging for physicians. The physicians considered themselves to be autonomous decision-makers by virtue of their medical knowledge and their legal position of responsibility for the final decision regarding treatment and care options. The physicians had no systematic or planned communication strategy to involve the patients in decisions about treatment. Identified barriers for not involving the patients include the physician's assessment of the acuteness of the actual situation, shortcomings in communication, and organizational difficulties.

In Study II, the findings show that the nurses found themselves operating within a cure-oriented biomedical treatment culture wherein they were unable to stand up for the caring values. Additionally, the findings imply that nurses need a stronger awareness of their legal and ethical responsibility as nurses to be able to advocate for their right and the right of their patients to be included in decision-making processes.

Findings in study III show that the participating patients experienced life as fragile and burdensome, interrupted by unpredictable and frightening exacerbations of their disease. The patients needed predictability in terms of involvement, compassion and care. Even though healthcare legislation and ethical codes for both physicians and nurses include the obligation to ensure that patients are informed, and that their values and preferences are taken into consideration in decision-making processes, the results from this study uncover that this is not the case in practice.

Conclusion: Overall, this thesis demonstrates that neither patients nor nurses are included decision-making processes regarding mechanical ventilation or noninvasive ventilation. This is unacceptable. To ensure improvements and to promote respect for the autonomy of patients, healthcare professionals should initiate discussion about the patient's preferences regarding treatment, and their hopes and their worries about future life and possible death. Ideally, it should be initiated when the patient's health condition is stable. This requires clear leadership providing and an interdisciplinary culture that ensures patient involvement.

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List of papers

This thesis is based on the following original papers referred to in the text by their Roman numerals:

- I. Jerpseth H, Dahl V, Nortvedt P, Halvorsen K. Considerations and values in decision-making regarding mechanical ventilation for older patients with severe to very severe COPD. *Clinical Ethics*, vol. 11, 4: pp. 140-148. First Published July 5, 2016.doi:10.1177/1477750916657657
- II. Jerpseth H, Dahl V, Nortvedt P, Halvorsen K. Nurses' role and care practices in decision-making regarding artificial ventilation in late stage pulmonary disease. *Nurs.Ethics* 2016 Jan.27. pii:0969733015626600 doi: 10.1177/0969733015626600
- III. Jerpseth H, Dahl V, Nortvedt P, Halvorsen K. Older patients with late-stage COPD: their illness experiences and involvement in decision-making regarding mechanical ventilation and noninvasive ventilation. *J Clin Nurs*. Submitted

Abbreviations

ACP	Advanced Care planning
COPD	Chronic obstructive pulmonary disease
EOL	End-of life
EOLC	End-of-life care
EXTRA	Norwegian Extra Foundation for Health and Rehabilitation
FEV1	Forced expiratory volume in one second
FVC	Forced vital capacity (litre)
GOLD	Global Initiative for Chronic Obstructive Lung Disease
HIOA	Oslo and Akershus University College of Applied Sciences
ICU	Intensive Care Unit
LHL	Norwegian Heart and Lung Association
MV	Mechanical ventilation
NIV	Noninvasive ventilation
RU	Respiratory unit

1 Introduction

'Last time I was hospitalized I thought I was about to die. The doctor told me subsequently that I would not receive that lifesaving help again. I am so afraid; I know there will be a next time and then I will not receive the treatment I need to survive. I still want to live a little longer' (Female patients with late-stage COPD, 64 years old).

This patient expresses the agenda of this thesis and highlights the themes regarding decision-making processes. Advanced technology like mechanical ventilation (MV) and noninvasive ventilation (NIV) for patients with Chronic Obstructive Pulmonary Disease (COPD)-exacerbation has made it possible for patients to survive crisis, but the treatment also raises difficult questions regarding tough priorities and the possibility of futile and undignified treatment in the end stages of the disease. Decisions about future treatment are often complicated, complex, and challenging ethically and emotionally as well as medically. Studies shows that Intensive Care Units (ICU) physicians and nurses experienced a growing ethical dilemma with older patients having marginal benefits of ICU treatment at the end of life (1 , 2 , 3). This dilemma particularly involved elderly patients with high pre-morbidity and chronic illnesses, such as patients in late-stage COPD. Informants claimed that often little documentation existed regarding patients' previous medical conditions, as well as their preferences, perspectives and values with regard to advanced life-prolonging treatment in terminal stage of illness (4). Legal regulation and guidelines for patient's care and health care priorities in Norway emphasize patient participation in decision-making about own health, medical treatment and care (5 , 6 , 7). However, studies show that healthcare personnel rarely engage in dialogue with patients with COPD regarding end-of-life (EOL) decision-making processes, even though most such patients seem to want to participate in making decisions about end-of-life- care (EOLC) (8 , 9). Caring and compassion for the particular and concrete patient, and understanding his or her lifeworld and history of illness is imperative for good and right priorities at bedside. How much, how long and how advanced treatment should be given the individual patient in late stage of COPD? Which considerations and values influence the decision regarding MV or NIV for this patient? How do the patients themselves experience their illness and how do they perceive being included in the decision-making processes? These questions constitute the main issues of this dissertation.

Clarification of concepts and delimitations of the study

Moral dilemmas and ethical issues

In this thesis the concepts of ethical dilemmas, moral dilemmas, and ethical problems are used inconsistently. The focus of the study was on participants' experiences of what was perceived as ethically or morally problematic in the decision-making processes related to providing ventilation support for late-stage patients with COPD.

Moral dilemmas are described by Beauchamp and Childress (10 p. 11) as

'circumstances in which moral obligations demand or appear to demand that a person adopt each of two (or more) alternative but incompatible actions, such that the person cannot perform all the required actions'.

Delimiting the gender perspective

This study involves men and women. However, the gender perspective is not taken into account in this thesis. Gender differences and issues were not a primary interest and the sample is too small to make any kind of conclusion related to gender differences.

2 Background

This chapter provides an overview of literature and subjects that have been central to this study. First, it offers an overview of the medical field related to COPD as a disease. Then, it presents the patient's perception of living with late-stage COPD, and their competence in decision-making. Next, it presents the healthcare personnel's considerations and role in decision-making regarding NIV or MV.

Chronic obstructive lung disease (COPD)

Definition, risk factors and epidemiology

COPD *“is characterized by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious particles and gases. Exacerbations and comorbidities contribute to the overall severity in individual patients”*(11, p. 2).

The cardinal symptoms of COPD are dyspnea, chronic cough and/or sputum production. The disease develops progressively and increases in severity with time (11). The most *common* risk factors are tobacco smoking, smoke from home cooking and heating fuels, occupational dusts and chemicals or familiar history of COPD. COPD prevalence, morbidity, and mortality increase with age. The changing pattern in tobacco smoking has led to equalization in the prevalence of the disease in men and women (12). Although cigarette smoking is the best-studied COPD risk factor, there seems to be a complicated gene-environment interaction. Risk factors are related to gender and whether a person takes up smoking or experiences certain occupational or environmental exposures. The risk is higher in people with lower socio-economic status, but it is not clear whether this pattern reflects exposures to indoor and outdoor air pollution, crowding, poor nutrition, infections, or other factors that are related to low socioeconomic factors (13).

The single genetic risk factor that is best documented is a severe deficiency of alpha-1 antitrypsin. Alpha-1 antitrypsin deficiency leads to increased destruction of the alveolar wall and lung parenchymal tissue, which leads to emphysema. However, only a small proportion of the world population has alpha-1 antitrypsin deficiency, and interactions with environmental factors such as smoking may increase risk of COPD (11).

COPD is the only disease whose age-adjusted mortality continues to increase. Worldwide, 65 million people have COPD and it is calculated that by the year 2030 the disease will become the third most

common cause of death in the world (11) . About 300 000 (6) live with COPD in Norway and the prevalence has increased from 7% to about 14 % during the last decade (6 , 14).

Pathogenesis and comorbidities

The main characteristic of COPD is a chronic inflammatory process in the central and peripheral airways. This chronic inflammation does not only exist in the patient's lungs, but affect the whole organism. At the present time, there are no answers as to why or how this chronic inflammation develops (11). Inflammation causes impairment and destruction of ciliary movement, which leads to stagnation of mucus and changes in the mucous membranes. The alveoli located in the end of the tracheobronchial tree may be injured and may lose elasticity and/or may be damaged and lead to less area to use for gas exchange. The COPD diagnosis encompasses two conditions; chronic bronchitis (chronic inflammatory process) and emphysema (permanent destruction of alveoli) (11).

Because COPD often develops in among middle-aged long-time smokers, patients frequently have a variety of other diseases related to either smoking or aging. A comorbidity is usually defined as a disease coexisting with the disease of interest (15). Comorbidities for patients with severe COPD are common and have a significant impact on a patient's prognosis. The most common comorbidities are cardiovascular diseases (25%), cancer (mainly lung cancer 20–33 %) and other causes (30%) (11). Depression and anxiety are common and occur 3–6 times more frequently compared to age-corresponding healthy subjects (16).

Figure 1. Classification of airflow limitation severity in COPD and Risk in COPD

	FEV₁	Exacerbation (per year)	Hospitalizations (per year)	3-years Mortality
GOLD 1: mild	FEV ₁ ≥ 80% predicted	?	?	?
GOLD 2: moderate	50 % ≤ FEV ₁ < 80% predicted	0.7–0.9	0.11–0.2	11%
GOLD 3: severe	30 % ≤ FEV ₁ < 50% predicted	1.1–1.3	0.25–0.3	15%
GOLD 4: Very severe	FEV ₁ , <30% predicted	1.2–2.0	0.4–0.54	24%

Adapted and modified table ‘Classification of Severity of Airflow Limitation in COPD and Risk in COPD’ Based on table 2.5 and 2.6 (11 p 31)

Exacerbation and noninvasive ventilation and mechanical ventilation

Physiologic parameters for lung function are often expressed as forced expiratory volume in one second (FEV₁) and forced vital capacity (FVC). These values are compared with those for the normal healthy population and are expressed as a percentage of predicted value. An FEV₁/FVC ≤ 0.70 confirms airflow limitation (11). These values are important in assessing the degree of airway obstruction, but in recent years, it is more common to use a multi-dimensional tool to assess the COPD’s severity and future risk of exacerbation. Although the degree of airway obstruction is important, it has been realized that several factors should gain more attention. These factors include dyspnea, exacerbations, comorbidities including psychological disorders, regular physical activity, exertional desaturation, peripheral muscle mass, body composition, nutritional status, hormone balance, effort intolerance and quality of life (6 , 11 , 17).

An exact definition of exacerbation is not agreed upon. Both symptom- and event-based definitions have been described in the literature. The symptom-based definition is described as worsening or increased dyspnea, with or without sputum and sputum purulence. The event-based definition describes exacerbation as an acute event characterized by worsening of patient's respiratory symptoms that is beyond normal day-to-day variations, and leads to a change in medication (17). The risk of exacerbation significantly increases in GOLD 3 and GOLD 4. Since exacerbations increase the decline in lung function, deterioration in health status and risk of death, the assessment of exacerbation risk can also be seen as an assessment of the risk of poor outcomes in general. No single biological marker has yet been proved capable of assessing the severity of exacerbation (11).

With the exception of oxygen therapy, no standard treatment for COPD has been shown to have a mortality benefit (18 , 19). The treatment for exacerbation will differ depending upon the severity of disease. Initial management of dyspnea should always start with nonpharmacological measures, such as maintaining an upright position, cool air fans, breathing/relaxing exercises, and reassurance, with or without pharmacological therapy (20). In addition to long-acting bronchodilators, robust evidence supports the use of short-acting opioids as first-line choices for management of breathlessness is recommended, although variability exists in recommended starting doses and titration schedules (6 , 11 , 21 , 22 , 23).

NIV has become an established treatment modality for patients with acute exacerbations of COPD. NIV refers to delivery of ventilator support or positive pressure into the lungs without an invasive endotracheal airway, usually through a mask (24). The respirator supplies air with positive pressure in order to assist the patient's breathing. The difference in pressure between breathing in and breathing out facilitates the patient's breathing and supplies more air to the lungs (25). A survey carried out in the USA showed that the use of NIV to treat acute exacerbations of COPD increased more than 400% in one decade (from 1% in 1998 to 4.5% in 2008), and was associated with 42% reduction in the need of MV (26). Treatment with NIV plays a definite role in the management of acute hypercapnic respiratory failure and acidosis, and the use of NIV-treatment has shown to reduce rates of intubation and complication (24 , 27 , 28). The determinations for the use of NIV are acidosis ($\text{pH} < 7.35$), hypercapnia, tachypnea, severe dyspnea and the use of respiratory accessory muscles (29). Despite the overwhelming evidence justifying the use of NIV as support in COPD exacerbations, recent studies demonstrated that its application sometimes remains suboptimal when it comes to survival and relieve of dyspnea (30). Randomized controlled trials provide contradictory results regarding NIV treatment's

benefits on health status and survival in patients with late-stage COPD (31 , 32). A retrospective study found that patients with COPD being treated with NIV for the first time showed survival rates of 72%, 52% and 26% after 1, 2 and 5 years (33). The usefulness of NIV treatment to relieve dyspnea at the end of life has still not been adequately documented and is controversial (19 , 34).

International guidelines recommend a second complete evaluation of patient after a few hours of NIV use (35). When no improvements occur, the prognosis is uncertain. In presence of NIV failure, a decision concerning intubation or not should be made (36). The use of MV in patients with very severe COPD should according to the guidelines be influenced by the likely reversibility of the precipitating event, the patient's wishes, and the available of intensive care facilities (11 , 26).

Patient perception of living with late stage COPD

Studies indicate that quality of life for patients suffering from late-stage COPD is characterized by physical symptoms like breathing problems, exhaustion and pain, compounded by comorbidity, psychological distress as anxiety, depression and social isolation (18 , 37 , 38 , 39 , 40 , 41). The disease trajectory for COPD patients involves years of chronic illness with periods interrupted with exacerbation. More than 60 % of patients hospitalized due to acute exacerbation of their COPD are readmitted within a year, and the need for repeated hospitalizations is associated with marked reductions in patients' quality of life (11). The course of the disease may lead to a negative downward spiral, during which the patient becomes increasingly disabled, and a negative change in COPD-related problems such as breathlessness may predict a worsening of depression and anxiety over time (42).

Breathlessness is a common, complex symptom in COPD, with a prevalence increasing up to 94% in late- stage COPD, and the intensity scores remain higher over a long period of time among the patients (43 , 44). Breathlessness is a subjective experience derived from interactions between multiple physiological, psychological, social and environmental factors (45). One observational study of 125 patients from five countries showed that anxiety evoked the patients' most concern because they worried about suffocating, death and worsening of their symptoms (46). The acute need for help is often related to increasing breathlessness (exacerbations). The literature addressing the patients' experiences of acute exacerbation are limited (47). However, patients in qualitative studies describe an acute exacerbation of COPD as a life-threatening condition that is frightening and extremely traumatic.

Studies using narrative research described the patients' feelings of being near death during episodes of exacerbations (48 , 49).

Even though the prognosis is about the same for COPD as it is for lung cancer, patients with COPD rarely received planned end- of- life care (EOLC) (50 , 51 , 52). The patients are more likely to receive aggressive treatment during the later stages of the disease, including MV and NIV, at the same time it seems like this treatment is increasingly used as an option of last resort for patients who are dying of respiratory failure (53). The aggressive use of NIV and MV in the later stages of disease might lead to uncomfortable experiences, and in many cases, such treatment actually prolongs suffering, as well as the dying process.

Patients competence in decision-making regarding NIV or MV

Decisions regarding NIV or MV can only be fully understood in a context where patients, next of kin and health care personnel are incorporated into the processes where organizational and cultural factors also play a major role. The decision-making process is rooted in relevant legislation, professional ethics and professional knowledge and assessment of the situation, including values and preferences for the patients and their next of kin.

Norwegian legislation and health care regulations highlight that decisions involving serious intervention should be based on an agreement between patients, their families, and health care professionals in order to ensure the best quality of care corresponding to the patients' values and preferences (5 , 6). Hence, patients with severe COPD have a legal right to be involved in making decisions about their treatment options and goals related to development of their illness. According to the Norwegian Patients' Rights Act, the principle of autonomy should be based on informed consent (54). Respect for the autonomy of competent patients is regarded as a universal and *prima facie* moral principle in medical ethics (10). Studies show that most of the patients with severe COPD want information about diagnosis, prognosis and treatment-and care options (55 , 56). Additionally, they want the communication to concentrate on limited open-ended questions. These questions should be structured as well-informed, concrete options regarding medical treatment and care, transparency about what will happen next, and what dying might be like in order to reduce confusion, suffering and avoid non-beneficial care (38 , 57).

The making of EOL decisions is about limiting intensive treatment for patients with a serious deterioration of COPD. In this study, we define EOLC as care intended "to assist persons who are

facing imminent or distant death in order to have the best quality of life possible till the end of their life regardless of their medical diagnosis, health condition or age (58). Using this definition, we hold it open whether the death is sooner or later, in line with the difficulties of setting an accurate prognosis in COPD.

The need for NIV or MV mainly arises during the phase of illness in which fear of imminent death and dying may be prominent and hence may cause great emotional strain for the patients, their family and health care professionals. In this acute situation there is no time for discussions regarding the decisions about future treatment. These discussions are in need to be taken when the patients are in a stable phase of the disease. To ensure that the decision is right, it is extremely important that the patients' values and preferences are known and the patients are informed, and ensure that the information is understood (7). However, several studies show that patients with late stage COPD do not receive sufficient information about their diagnosis, prognosis and treatment options during the late stages of their illness. Additionally healthcare professionals are often unaware of their patients' values and preferences, and patients' themselves have only limited knowledge about their illness trajectory (55 , 56 , 59 , 60 , 61).

In late-stage COPD, patients often live in a cycle of intermittent exacerbations, with declining health and decreasing functional status. When they are hospitalized, they receive medical assistance in the form of NIV or MV treatment that will temporarily ease their breathing problems 'here and now'. However, studies show that the patients with late stage COPD are not offered a dialogue to discuss their situation when their condition permits such a dialogue (8 , 37 , 62 , 63 , 64). This happens in spite of the fact that most of patients with COPD are able to discuss preferences for EOL-care and want to take part in decision concerning their own treatment and care, and how they might die (9 , 55 , 57 , 65 , 66 , 67 , 68). Since patients with severe COPD rarely have planned palliative care, older patients often die in hospital during a period of acute exacerbation without having had the opportunity to express their choices or wishes regarding EOLC (52 , 64 , 65).

Healthcare personnel's consideration and role in decision-making regarding NIV and MV

Both Norwegian health care policy guidelines and healthcare legislation have mandated the involvement of patients, their next of kin and a multi-disciplinary team to participate in decision-making processes. Additionally, it is the health care personnel's responsibility to initiate such discussion (5 , 6 , 7).

The decision-making can be understood as the process of collecting and integrating different aspects of information about a situation in order to generate alternative problems or hypotheses (7). The EOL practice for patients with late stage COPD could possibly concentrate on three proposed options: mechanical ventilation (endotracheal intubation), “ceiling” non-invasive ventilation, and palliation of symptoms with oxygen and morphine (64).

There has been an increased emphasis on the importance of patient-physician communication about EOLC with patients suffering from severe COPD (57 , 60 , 64). This conversation should include discussion concerning the goals for care, the patient’s attitudes towards the benefits and burdens of the various options as his or her clinical situation changes, and clarification of the consequences of each treatment. Communication must be grounded in compassion for patients as well as humility. Humility is linked to the fact that there are limitations on how many aspects of each individual’s illness experience are understood (69 , 70).

As mentioned earlier, studies have shown that physicians rarely engage in a dialogue with COPD patients regarding end-of-life decision-making processes (8 , 9). The unpredictable course of the disease is characteristic of the COPD trajectory and makes it difficult to determine when death is likely (62 , 71). To clearly identify the point of transition to palliative care is therefore challenging, and it is almost impossible to provide patients with realistic information about prognosis. This may lead to an absence of communication often described as “prognostic paralysis”, in which the clinicians responsible for patients with uncertain illness trajectories prevaricate concerning EOL issues (40 , 72).

Caring for these patients is a multifaceted process where nurses play a crucial role. The national guidelines also state that all groups of personnel relevant to treatment and care should be involved in decision making processes (7). Nurses are arguably the health care professionals who spend the most time with patients and their families. Nurses often hold a key position in coordinating the overall care for COPD patients, and might be the first to observe changes in patients’ condition as well as the eventual need for EOLC. Together with the caring values such as empathy and moral sensitivity towards patients’ suffering, nurses can ask questions about patients’ values and preferences in a sensitive way without causing too much distress (73 , 74 , 75). EOLC represents an important part of nurses’ professional responsibilities in caring for patients, and research describes the importance of nurses’ role in EOL decision-making (76 , 77 , 78). Research also seem to indicate that giving nurses more responsibilities in EOLC represents an effective use of health care resources with regard to these patients (79). Despite this, a number of international and

Scandinavian studies demonstrate that nurses are rarely involved in decision-making processes regarding EOLC (4 , 73 , 74 , 80).

A recent report from The Norwegian Knowledge Centre for the Health Services, states that there is a need for research about what happens during the decision processes and what are important and necessary factors for making these decisions as good as possible (81). To gain more knowledge regarding the health care professionals' values and considerations regarding decision-making about MV or NIV in late stage COPD, and how the patients experience their role when decision about their treatment and care are made is therefore of significance.

3 Aims of the study

The overall aim of the study is to gain empirical knowledge of the considerations and values that influence decision-making regarding noninvasive ventilation and mechanical ventilation in late stage COPD.

The specific aims of the study are the following:

1. To explore consideration and values that influence decision-making regarding MV and NIV treatment in older patients with late stage COPD. Furthermore, the study aims to elucidate how physicians working in ICU wards and physicians working in RU wards involve their patient in decision-making process (Paper I).
2. To explore how intensive care and respiratory nurses experience their own role and care in the decision-making process. Furthermore, the study aims to elaborate how nurses perceive the patients' role in the decision-making process (Paper II).
3. To gain knowledge about how patients with late-stage COPD experience their illness. Furthermore, it aims to explore how patients with late stage COPD perceive that their preferences are taken into account in decision-making processes concerning treatment options such as MV or NIV and end-of-life care (Paper III).

4 Theoretical perspectives

This thesis encompasses different aspects of difficulties one encounters, both as a patient and as a health professional, in making concerned decisions regarding patients with late-stage COPD. Limiting MV or NIV for patients with a serious deteriorating COPD raises many challenges of EOL decision-making and EOLC. The themes raised are professionally, ethically and legally challenging. This chapter will present relevant ethical principles and guidelines, concepts and a legal framework with regard to decision-making in the best interest of these patients.

Clinical ethics

Many situations about continuing or discontinuing MV or NIV treatment for patients in late stages COPD raise moral dilemmas, implying decisions concerning care at the end-of-life. These decisions have severe consequences for the patient, their next of kin and the health care professionals. The ethical aspects of the decision-making process in clinical care are not limited to theoretical, medical or biomedical ethics, but are value choices that arise in the clinical setting. Important ethical considerations, such as considering benefits or burdens of treatment, quality of life assessments, and the patient and families' informed preferences are crucial in these clinical settings.

Clinical ethics expands on professional ethics, and includes different health care professionals' norms. The ethics of the medical profession focuses on ethical values regarding medical treatment and care. What characterizes clinical ethics are interactions between multiple actors with different professional perspectives of value, knowledge basis and roles (82). This expanded understanding of ethics encapsulates interaction between patients, their next of kin and all health care professionals, not only the physicians. Clinical ethics is a practical discipline that provides a structured approach for assisting the health care professional in identifying, analyzing and resolving ethical issues in clinical medicine (82 , 83). Jonsen (83) suggest that in every clinical case, when seeing an ethical problem, one should analyze the situation with reference to four topics: (1) Medical indications, (2) Patient preferences, (3) Quality of life and (4) Contextual features (including the social, economic, legal and administrative contexts in which the case occurs).

In this practical orientation, clinical ethics is different from the theoretical ethics, whose primary concern is to clarify and justify values and principles on the basis of judgment between right and wrong,

good and evil. Clinical ethics is about choices, decisions and those actions that are beneficial and good for the patient in each particular case of clinical practice. Theoretical medical ethics will act as an important directive and be a corrective to dominant practices in health care. Sometimes theoretical ethics may act as the starting point and will be applied to theorize a case at hand in order to reach a conclusion about what should be done (84). The theory may prevent practical ethical concerns from becoming a legitimate tool for the part with most power. At the same time, it is important to underline that it is in the clinical context, and in the particular situation's complexity, that theoretical ethics of medicine have the opportunity to show what it is worth (85).

The ethics of the medical profession focuses on ethical values regarding medical treatment and care, and in the Norwegian legal context, the physician is the authorized decision-maker, the one who has the final say in medical matters, when the patient is not competent to decide. However, competent patients have the right to deny treatment with potential benefit. Patients, on the other hand, cannot make requirements for treatment considered by the physicians as not in patient's best interests (5).

The four principles approach

The four prima facie principles, beneficence, nonmaleficence, respect for autonomy and justice, afford a good and widely acceptable basis for making good medical ethics choices (10 , 86). For patients with late-stage COPD, the principle of autonomy in decision-making may be the most important principle, since it concerns the patient's right to self-determination. On the other hand, it is also important to illuminate the balance between autonomy and beneficence, because there is always a risk that health care personnel may act paternalistically in order to do well. However, sometimes extremely challenging situations may occur in which the patient makes a decision that is detrimental to his or her health. These can be cases where the patient refuses potentially beneficial care or does not take beneficial medical advice seriously.

The four principles all derive from common morality and professional traditions in health care. Common morality is defined as 'the set of norms shared by all persons committed to morality'(10 p.3). The principles do not constitute a general ethical theory, but each of them represents a prima facie obligation, meaning that it should be 'fulfilled unless it conflicts with an equal or stronger obligation' in a particular situation (10 p.13). This assessment is called 'balancing' and should be performed in cases where more than one principle is involved (10 p.13). In our study, proper balancing is related to cases

when there is a question about the extent to which respect for autonomy of patients should have priority over professional beneficence.

These ethical principles have a long tradition in medicine, dating back to the Hippocratic Oath. However, the principle of autonomy is relatively new. In accordance with rising educational levels and the development of a market orientation in society in general and health care in particular, the right to self-determination is emphasized. In health care, this change implies challenges to the paternalistic tradition that used to dominate the medical profession (10). Another reason for the growing importance of autonomy as a principle, is the Nuremberg trials, which clearly proved that the beneficence of a medical professional cannot be taken for granted (87). The shift occurred from the beneficence model (characterized by maximum physician discretion) to the autonomy model (emphasizing increased patient involvement) at the turn of the twentieth century (88). There has been considerable resistance to this change, which leads to greater emphasis on patients' autonomy, especially among physicians. This resistance is due to a paternalistic attitude, where the physicians consider themselves as the autonomous decision-makers (54 , 85). Paternalism can be understood as the intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to goal of benefiting or preventing or mitigating harm to person whose preferences or actions are overridden (10 p.217). A distinction exists between soft and hard paternalism. In soft paternalism, an agent intervenes in life of another person's on grounds of beneficence or nonmaleficence with goal of preventing non-voluntary conduct. Hard paternalism on the other side, will restrict forms of information available to the person or will otherwise override the person's informed and voluntary choices (10 p.217).

The principles of nonmaleficence and beneficence

One of the basic principles in medicine and nursing is to prevent premature death and suffering due to illness, and to save lives. To cure, care and comfort is stated in the Hippocratic principle, but of first and foremost to do no harm (89), later known as the principle of non-maleficence in the principle-based ethics developed by Beauchamp and Childress (10).

The use of advanced technology like NIV and MV in care for older patients with severe COPD, raises difficult questions regarding the dilemma of benefits, and what inflicts harm. The principle of nonmaleficence means not to inflict harm. This principle has been closely associated with the maxim 'above all do no harm'. However, there is no clearly defined distinction between not inflicting harm and

providing benefit. Rather, these two outcomes are to be understood as being on a continuum of morally relevant considerations (10). Second, it can also be difficult to assess what is to be considered harmful, and in particular, what is unjustified or unnecessary harm in cases where the benefit for the patient might be evident and the patient endorses the particular therapy. For instance, NIV or MV can be burdensome and prolong suffering, but can also save and prolong the patient's life.

The principle of beneficence reflects a moral obligation to act for the benefit of others. The utility form of benefits requires a focus on overall result, by balancing benefits, risk, and cost (10). For nurses and physicians, the principle of beneficence expresses a duty to be of benefit to their patients, to do something good for them, precisely by virtue of being a doctor or a nurse (89). In new Norwegian guidelines for prioritizing in health care, it is stated that health-related quality of life in terms of good years of life, should be a part of decision-making processes in prioritizing in health care (90). However, it is difficult to predict and find the indicators of an appropriate level according to the concept 'good years' for patients with late stage COPD.

The intention of healthcare personnel to do something good for the patient might be in conflict with the respect for autonomy of patients. There is a risk of a paternalistic attitude in the health care relationship when someone in an authoritative position determines patient's best interests without knowing the patient's own wishes and preferences regarding life-prolonging treatment.

The principle of justice

According to Norwegian prioritization policies, the principle of justice is a core value and basic principle for welfare policy (85 , 90 , 91). In this empirical study, justice is not an explicit topic, although there is an ongoing debate regarding limited resources in health care. In particular, regarding the patients in this study, the conflict between individual care and attention to the particular patient can conflict with the justified needs of other patients in their legitimate demand for hospital or home care. Patients with late-stage COPD have great needs of nursing and medical care, their quality of life is often low (37 , 38), and the question of what may be in the patient's best interests: further medical treatment or palliative care, may be raised. In addition, the question of what is futile treatment, or which treatment is cost effective, may be raised, when the cost of further life-prolonging treatment is high, while the benefit for patient in terms of life years and quality of life is marginal or very low.

There is an absence of consensus on a single theory of justice with regard to distribution of health care (10). The principle of justice has its root in ancient Aristotelian philosophy; “*Equals must be treated equally, and unequal must be treated unequally*” (10 p.250). That equals ought to be treated equally provokes no debate, since it makes no specifications with respect to which individuals should be considered as equal. The principle is however, more complex regarding the distribution of limited resources. Health care professionals are obligated through their social mandate to deliver health care resources fairly and efficiently with an overall distributive concern for the health care budget (92). However, studies show that just as significant for health care professionals are the ethical ideals of individual concern and attention to particular patients. Their moral considerations underlying clinical priorities take the physician’s and nurse’s responsibility for the particular patient to be a primary duty (1 , 93 , 94).

The principle of autonomy

The precise meaning of the term is disputed. Discussion of what it means to respect patient autonomy often distinguishes between autonomy of actions, including choices and decisions, and autonomy as a characteristic of persons or lives, often referred to as personal autonomy. In this study, the concept of autonomy will be focused on autonomous actions, following Beauchamp and Childress’ arguments, which claim that personal autonomy is neither necessary nor sufficient for a decision to be autonomous. Patients may sometimes make autonomous decisions even though they generally are incapable of doing so. Autonomy refers to personal self-governance, free from controlling interferences by others and from personal limitations that prevent choice (10). Patient autonomy may have at least three different meanings:

1. As a principle, it implies respect for the patients’ wishes and needs when decisions are taken.
2. Autonomy can be understood as a personal characteristic, i.e. the capacity to act freely in accordance with a self-chosen plan and as a corresponding right to make decisions about one’s own health.
3. Autonomy may be defined as a right, limited to a definition as autonomous choice, autonomous decisions (10 , 85).

The right of patients to make autonomous decisions is rooted in accepted ethical principles as well as Norwegian Health Care Legislation (5 , 85). In medical ethics, respect for patient autonomy of competent patients is regarded as a universal and absolute moral principle. This implies that ‘a person

who is affected by a medical decision and who must live with its consequences should also be involved in making the decision and have the right to abstain from health care' (89 p.32). However, there needs to be a balance between the patient's autonomy and the health care professionals' autonomy. The patients' autonomy in health care gives them the right to be a part of the decision and to say no to suggested treatment. A principle of respect for autonomy is invoked in discussion about confidentiality, fidelity, privacy and truth telling, but is most strongly associated with the idea that patients should be allowed or enabled to make autonomous decisions about their health care (10). However, the patient has no positive right to demand treatment or actions which are not in his/her interest or are contrary to professional responsibility and/or the autonomy of the health care personnel (89 , 95). A central question is 'should the health care personnel accept the informed but poor choice of a patient on the grounds of respecting autonomy? Is there an ethical obligation to persuade the patient otherwise and if so from where does this obligation arise?' This question elucidates the possible conflict of interests between the four principles of ethics, especially when it comes to the relationship between the right to autonomy and the principle of beneficence. In the clinical context, respect for autonomy may constrain both the principle of beneficence and the principle of nonmaleficence when the physicians are not given permission by their patients to treat them beneficially. On the other hand, the role of the physician is to offer autonomous patients their beneficial services, not to impose their own will (86). Lay people do not possess the professional knowledge, but it is an obligation for health care professionals to inform them and enable the competent patient to make consent regarding their own wishes for care and treatment (5).

Informed consent, decision-making competence and patient's best interest

An informed consent in health-care services is an autonomous person's authorization of the health care professional actions towards the person (96). While autonomy might be understood as a principle, informed consent is a moral action that justifies the practice (10). In clinical decision-making, the principle of autonomy is upheld by informed consent. The procedure of obtaining informed consent may increase patient participation and prevent unwanted treatment and care. If a patient must provide informed consent prior to commencement of treatment, it follows that the patient can refuse the recommended treatment. This leads to the next central challenge in clinical work, namely to decide whether patients can be said to be competent to make a decision or not.

Autonomy, integrity and informed consent are included in the same ethical reasoning. Integrity, the requirement of respect for human dignity is the most fundamental. However, the three concepts will

presuppose each other due to the fact that informed consent is a means to avoid infringement of autonomy and integrity (89). Assessment of competence protects the rights of competent patients to make decisions for themselves and protects incompetent patients from consequences of decisions. The greater consequences a decision has, the more stringent requirements should be put to consent. The decision-making capacity is not an absolute sense and may be situational and vary from hour to hour. The decision-making capacity should therefore always be assessed related to the decision to be taken (7).

The most important aspects of judging competence is how patients reach their decisions, rather than what they decide. There is a matter of debate about exactly what mental abilities are necessary for competence or decision-making capacity (97). However, many standards require that a patient have a relatively stable set of goals and values; be capable of understanding the consequences of decision, including its risks and benefits; be able to reason about the relevant information and communicate a choice; and be able to appreciate how the decision will affect them personally (89 , 97). Beauchamp and Childress also mention non-control as a condition of autonomous action. This means that a person is free of controls exerted either by external sources or by internal states that rob the persons of self-directedness (10).

A stable set of goals and values require plans in the form of presentations of series of events proposed for execution of an action. An action is not autonomous if the person does not adequately understand it. Conditions that may limit understanding include illness, pain and depression. A full understanding of medical facts, or all relevant circumstances, is however not required for an action to count as autonomous, because it seems meaningless in the practical world (10). However, necessary information regarding health condition, diagnosis, prognosis and treatment options is necessary to make the decision valid (5). As mentioned, patients with severe COPD are frequently not sufficiently informed about their diagnosis and treatment options. However, it is difficult to decide what constitutes the necessary information. The information about diagnosis and prognosis may include 'bad news', and be harmful if the amount of information or speed of its delivery goes beyond what the patient wants at that time. The essential step in the process of giving information and facilitating decisions is to uncover the patients' values and preferences for both the involvement in decisions, and to which extent the patient wants information about his or her condition. Therefore, the information process must be individual and adjusted to the patient's needs and wishes.

Patients with late-stage COPD are often in a situation where they are in need of acute medical assistance. The acute condition may present a considerable challenge to determining the decision-making capacity. Impairments of rational and mental capacity in heterogeneous groups such as acutely medically ill patients in hospital have been less extensively studied. However, one study has demonstrated that clinical teams rarely identified patients who did not have mental capacity (98).

If the patient lacks decision-making competence, the decision has to be transferred to others. The premise for surrogate decision-makers, whether they are health care professionals or next of kin, is that the decision maker will make the decision in the patient's best interest. The term 'best interest', applies to the health care personnel's obligation to act beneficently by maximizing benefit through a comparative assessment that locates the highest probable net benefit for patients. Beauchamp and Childress define the best interest standard as one in which a surrogate decision maker must determine the highest net benefit among the available options, assigning different weights to interests the patient has in each option, and discounting or subtracting inherent risks and costs (10 p.227). In Norwegian Healthcare Legislation there is no clear definition of patients' best interest as a principle, but it should only be used when the patient is unable to consent (81). Promoting the patients' well-being is a fundamental value in medical practice. Well-being is designed to signal the respect in which the fundamental goal of medicine is in part subjectively determined by the particular patient's aim and values (89). Health care personnel need to initiate conversations with patients to gain knowledge about their values and preferences. The patients' best interest should be based both on medical and care knowledge, supplemented with an individual approach to assessing and respecting the patients' values and preferences (7).

The legal framework and other official frameworks regarding decision-making

Patients' involvement in medical decisions has become an increasingly important part of health policy in Norway. The patient is entitled to participate in the implementation of his or her health care. This includes the patients' right to participate in choosing between available and medically sound forms of examination and treatment (§1). The form of participation should be adapted to individual patients' capacity to give and receive information (5). The legal right of participation is also implemented in Official Norwegian Reports (NOUs) where the patients' right to be included is specified as beneficial (90).

Health care and treatment can only be provided with the patient's consent, unless a legal authority exists giving valid reasons for providing health care without consent (5). One valid reason is emergencies. According to Norwegian Health Care Law §7, health personnel are obligated to act in emergency situations for the benefit of patient, even when he or she has decision-making capacity and refuses treatment. An exception from this 'duty to receive acute life-saving treatment' is if the patient is considered to be dying (54 , 99). As far as I know, Norway is the only country that has a law imposing coercive measures against a competent patient's wish in cases of emergency (100 , 101). Moreover, patients with late stage COPD are quite often in a situation where they are in need of acute respiratory assistance in the form of NIV or MV treatment. The decision to accept or reject mechanical ventilation support might be difficult. An imperative to treat might be strong in acute situations with respiratory distress. Also, since the patient with late- stage COPD has rarely expressed his or her references and values with respect to future life-prolonging treatment, the action regarding MV or NIV treatment is mainly based on the physician's medical experience and personal preference (9 , 38 , 60). Advanced requests or directives relating to the limitation of life-prolonging medical treatment in certain situations, or the appointment of a proxy for use if patients are unable to communicate their wishes, is possible in Norway as in in many other countries. However, in contrast to most countries within the EU, these are not legally binding in Norway (81). Patients with severe COPD may therefore subject to being over- or under-influenced by their physicians and there is a risk for a paternalistic decision according to the physician's own attitude, and his or her understanding of the patients' situations. However, the Patient Rights Act states that the patient has a right to say no to treatment even though there is a life-threatening condition, if the patient is defined as dying (5, § 4-9). It is difficult to know when patients with late stage COPD status change from "seriously ill" to dying. The traditional interpretation of dying is based only on objective medical facts, without taking the patients' personal perception of his/her own situation into account (102).

Patients with late-stage COPD have been ill for a long time and most of them have had many episodes with serious exacerbations. The patients should therefore have an opportunity to express their preferences when their condition is stable. According to the law an emergency situation is an acute situation where the patient needs treatment, *inter alia* to establish vital function or restrict a severe reduction in vital functions (99). That creates a need for distinction between a 'true' emergency and an 'expected emergency situation'. The legislators have not made such a distinction (102). Due to the gradual deterioration of the disease, it is a challenge to ensure that the period leading up to end-of-life is

accordance with the patients' wishes and preferences. Advanced care planning may be a way to contribute to ensure that the patients' values and preferences are elicited.

Advanced care planning

Advanced care planning (ACP) is recommended on a political level for patients with COPD (6 , 7 , 11). ACP for patients with severe COPD may be an important approach in prioritizing and coordinating health and care services meeting the best interest of the patients. ACP represents a process of open discussion between patients and their care providers on how their condition may affect them in the future. This includes discussions concerning the patients' understanding of their diagnosis and prognosis, as well as any concerns and preferences for care and treatment at the end-of-life. These discussions should, rather than promoting the making of binding decisions on treatment preferences, be an involvement in decisions about patients' care. In this way, ACP could potentially reduce concerns about patients receiving unwanted interventions and hospital admission, as well as providing opportunities for discussion about diagnosis and prognosis. Shared decision-making is a central element in ACP. In shared decision-making, both the patient and the health care professional make active and essential contributions through open dialogue, joint deliberation and mutual understanding (103 , 104). Despite these potential improvements in EOLC and an opportunity to optimize care, promote autonomy and empower patients, it is not commonly done with patients with COPD (38). The possible barriers for both health care personnel and patients are outlined in Chapter 2. Since the trajectory of COPD is unpredictable, it is important to underline the ACP about palliative care is most effective when employed alongside disease modifying therapies (19). Even though studies show that most of the patients with severe COPD want to discuss and take part in the decision concerning their goals for treatment and care, there are also patients who do not want to be included in these discussions (57 , 65 , 66 , 67 , 68). This underlines the need to be sensitive and to tailor the information needs to the individual patient. Houben (105) discusses the role of trained respiratory nurses in discussing ACP with patients and their next-of-kin in close cooperation with the responsible physician. Nurses have specific skills that may facilitate communication about EOLC. They can provide prognostic information, and support the patient's hope by understanding individual aspects of care with a focus on patient's quality of life.

5 Methodology and research process

In this chapter, I will begin with a brief introduction to phenomenology and hermeneutic in qualitative research. Additionally I will outline the researcher's preconception. Then, I will describe and reflect on the research process, how I have collected data, coded and analysed the material, and the ethical considerations that have arisen during the process.

In line with the study's overall objectives and research questions, I have adopted a qualitative, explorative design grounded on a phenomenological and hermeneutic approach. The empirical material for this study is derived from qualitative interviews, based on focus group interviews with physicians and nurses, and individual interviews with patients with late-stage COPD. The themes for investigation are decision-making regarding MV and NIV treatment in late-stage COPD. What influences the decision-making, and how do physicians and nurses involve the patients in decisions? How do patients describe their challenges related to their disease and their involvement in the decision-making process?

Epistemological considerations

I aimed to gain knowledge, explore and interpret the lived meaning of participants' own experiences and perspectives related to decision-making in complex and complicated settings. This study is inspired by both phenomenology and hermeneutics, where the philosophers Husserl and Gadamer, respectively, account for much of the philosophical foundations (106). Hermeneutics and phenomenology as philosophical approaches are epistemologically linked, and the distinction between them may seem artificial (107). The purpose of phenomenological research is to acquire a deeper and richer understanding of people's everyday experiences, in which inherent meanings often are implicit (108).

In qualitative inquiry, phenomenology is a term that points to an interest in describing and understanding the world as experienced by the subjects, with the assumption that reality is what people perceive it to be (106). Hence, phenomenology as a method is also an inquiry into phenomena of illness, suffering, etc., as these phenomena are experienced in the daily lives of the subjects. Phenomenology is an investigation into first persons' experiences as it seeks the essences, essential or invariant characteristics of phenomena and achieve this by interview (109).

The term 'lifeworld' is central in phenomenology. It refers to the meaning pattern that constitutes the background of our conscious actions, and it is concerned with the specific reality that we can experience

and are familiar with by acting. We both sense and feel in relation to the world that we live in, as it reveals itself to us in our consciousness. This lifeworld should be the basis for describing phenomena (110). By choosing to do individual interviews with the patients, we were interested in the phenomenon of illness (late stage COPD) as it is immediately experienced (illness-as-lived) and the existential predicament in how they experienced being included in the decision-making process. In the focus group interviews with the healthcare professionals, we wanted to gain more knowledge about the firsthand or direct description on phenomena of decision-making in all its richness and complexity.

A criticism that is raised against phenomenology is that purely descriptive approach is not sufficient to understand meaningful phenomena, since we all interpret what we feel and experience differently. A shift has therefore become common in qualitative research, where the purpose of interpretation is to achieve a valid understanding of text or action (106 , 111). In hermeneutic, comprehension develops through the entire processes of understanding and interpretation (106). From a hermeneutic viewpoint, the interpretation of linguistic, communicative and textual meaning is the central theme, with a specification of the kinds of meanings sought and attention to the questions posed to a text. According to Gadamer, new knowledge and previous knowledge are interconnected to each other in what he called the hermeneutic circle or “hermeneutic spiral”(112). In the process of understanding a message, we have our own horizons through which we understand the message, and at the same time, we need to understand the otherness of other persons. The hermeneutic process in research becomes a dialogue where the researcher moves from his or her preconception to new understanding. Also the findings will be strengthened when they are analysed and discussed in the light of previous knowledge (113). I have balanced theory and empirical facts in different stages of this research, strived to keep this balance, and viewed my preconceptions as an essential part of generating understanding and knowledge.

The researcher's preconception

In qualitative research, the researcher influence and shapes the process, both personally and professionally. It is therefore particularly important that the researcher reflect on his/her own role, through the whole research process. The perspective or position of the researcher shapes and motivates all research in some way, and diverse and equally valid understandings of the topic under study might develop (114). The researchers' background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, the analyze-process and the framing and communication of conclusions (106).

Reflexivity in qualitative research describes a process and an interplay between the researcher and researcher's work. Reflexivity starts with identifying important preconceptions, and in qualitative research, preconceptions are not the same as bias, unless the researcher fails to mention them (114). Our own self-understanding is a part of both the history we are a part of and the language we speak. Preconceptions might be verbal, not verbal or not possible to articulate at all (113).

Before I started the data collection, I spent four days at a hospital, because I wanted to observe the care given to patients with late-stage COPD treated with NIV. These observations was never meant to be a part of the data collection, but an update for myself, because it is a while since I practiced as a clinical nurse. Spending those days in the hospital was a valuable experience in order to gain a deeper understanding of the research field.

A central discussion in qualitative methodology is the balance between proximity and personal distance to themes in the research (115). When approaching this field I brought with me my background influences of humanistic values and biomedical logic as a nurse and teacher of nursing, as well as my familiarity with hospitals and patients. I have worked for many years as a nurse in acute wards. In my role as a nurse, I have often faced challenges related to decision-making processes regarding treatment of seriously ill patients.

In addition, my preconceptions are part of my personal identity and values. In my own life, I experienced that my father died from lung cancer when I was about twenty years old. Lung cancer and COPD have many similarities: the breathlessness, the coughing, the anxiety, the suffering and the experiences of stigmatization.

While working with this project, I gradually became aware of normative stigma in my surroundings and my own attitudes regarding smoking. I have never smoked. I feared being a representative for the "healthy paradigm", thus projecting prejudiced attitudes in the meetings with patients with late-stage COPD.

My preconceptions, both of being a nurse and my personal ones, were a clear strength in the research process, because I could recognize and understand the complexity in the themes raised in the study. On the other hand, they might have led to hasty or premature deductions, because the research field is well known. My preconceptions could bias my interpretations because it is easily to take some of the aspects for granted (116). It might also have kept important questions from being asked. Gadamer calls this

false prejudices, where the researcher does not separate what is his/her own and the participants' experiences of the phenomena (112).

Method

Qualitative research is appropriate when the aims of the research are not well understood and complex, and when one is seeking to understand various phenomena that are related to subjective human experience, practice and perceptions (106 , 117). Conducting qualitative research involves being concerned with how something is experienced, appears, and is done or expressed. It may be related to describing, understanding and interpreting or deconstructing subjective human experiences. It can be the meaning that an individual ascribes to his or her experiences, and actions at an individual or collective level, either specifically or abstractly (118).

The qualitative research interviews

The qualitative interview is an interpersonal situation where knowledge is constructed in the interaction between the researcher and the participants. The knowledge created by the interviews, is inter-relational and intersubjective. This means that various preconceptions, attitudes, experiences and interests meet, and the interview material will be a result of this interaction (106 , 119).

The method for data collection was focus group interviews and individual interviews. These methods for data collection fall within in same qualitative research tradition. We chose a combination of two data collection methods in order to investigate and explore the same underlying phenomena. The reason for this was a desire to produce data as truthful and complete as possible and to confirm the validity of the findings (120). Two focus group sub-studies and one individual interview sub-study were conducted. Sub-study I was performed with Intensive Care Unit (ICU) physicians and respiratory Unit (RU) physicians. Sub-study II consisted of nurses working at ICU wards and respiratory wards. Sub-study III consisted of patients with late- stage COPD (Table 1).

Table 1 An overview of the studies and papers on which this thesis is based

Study	Design	Data collection:	Participants	Settings	Paper
I	Explorative descriptive	Focus groups interviews 4 groups	14 physicians (7 ICU physicians) (7 RU physicians) Pilot study: One focus group with one RU physician and one nurse	2 University hospitals 2 district hospitals	I
II	Explorative descriptive	Focus groups interviews 6 groups	26 RNs 12 nurses working in ICU 14 nurses working in RU Pilot study: One focus group with one RU physician and one nurse	2 University hospitals 3 district hospitals	II
III	Explorative descriptive	Individual interviews	12 patients with late stage COPD.	10 homes 2 nursing homes	III

The focus group interviews (Papers I, II)

I choose to use focus groups as the data-collection method for healthcare professionals. This choice is related to the context of where and how the decision-making processes are usually conducted. In the hospitals, decisions regarding treatment and care are often subject to discussion. Focus group discussions might be a recognizable context to discuss these complex issues. Focus group center on the use of interaction among participants as a way of accessing data that would not emerge if other methods

were used (121). It is characterized by a nondirective style of interviewing, where the prime concerns is to encourage a variety of viewpoints on the topic in focus for the groups (106). It is one moderator that introduces the topics for discussion and facilitates the interchange. The moderator's task is to create an open atmosphere for the expression of viewpoint of topics in focus. The moderator should encourage participants to talk to one another in asking questions, exchange anecdotes, and commenting on each other's experiences and points of view (109). The use of focus groups as a data collection method reflects the view that attitudes and perceptions are not developed in isolation, but through interaction with other people. Focus groups are useful for exploring and discussing 'what', 'how' and 'why' the healthcare personnel think as they do when interacting with patients with severe COPD. These interviews capitalize on group dynamics and cultural understanding, and one can thereby obtain information that may not be available through individual interviews (106).

Pilot study

A pilot study consisting of a RU physician and a nurse working in a respiratory ward was conducted in October 2012. The main purpose of the pilot study was to test the interview guides for the focus group interviews. Additionally, both the moderator (HJ) and the assistant (KH) gained valuable skills and experience in arranging focus group interviews. Based on experience from the pilot interview, the questionnaire was revised so that it was more open-ended, and it was decided to interview physicians and nurses in separate focus groups. This was done to ensure a situation where the nurses and the physicians could talk more freely. Homogenous groups are important to ensure that the participants share a common background of experience and to prevent unnecessary tension in the groups. At the same, the composition of the group must be such that different experiences can be elicited in the interviews (122). Data from the pilot study was not included in the main study.

Sampling of participants of focus groups

The participants were recruited from two university hospitals and three district hospitals in eastern and western regions of Norway. It was necessary to collect data from several hospitals in order to obtain a broad content basis for the material (space triangulation) and maintain anonymity (116 , 120). All the hospitals provide advanced treatment and care, including NIV and MV for patients with COPD, as well as general healthcare for a broad section of the Norwegian population. The hospitals had an intensive care unit and a respiratory unit.

Participants were selected based on the extent to which they would contribute to the study aims, and whether they have had relevant experience (123). We wanted experienced participants, and the inclusion criterion was that physicians and nurses had worked bedside for the previous three months, and have had experience regarding decision-making about MV, NIV and EOLC.

In Sub-study I, 14 physicians were recruited (table 3). In Sub-study II, 26 nurses were recruited (table 5). The participants in each focus group came from the same hospital, mostly due to practical reasons, but also because they knew each other and this might have made it easier to communicate more freely. We chose to assemble the group of physicians from the ICUs and physicians from the RU in Sub-study I, and nurses from the ICUs and RU in Sub-study II (table 2 and table 4).

As can be seen from the composition of the six focus groups (Sub-study II, Table 4) there was one group with only nurses from the ICU and another group with only nurses from the RU. Due to the heavy workload in the ICU on the day the interview was scheduled, we had to split the focus group. We considered such a splitting of the group acceptable, since we already had four focus group interviews with nurses from RU and ICU wards. Nonetheless, we decided to conduct the final two groups in order to determine whether a group consisting of only nurses from the RU or ICU would allow the discussion to deepen and/or encourage new knowledge to appear (117). Another reason was that both the ICU- and the respiratory nurses wanted to partake in a focus group interview. In that respect, we also found it right to perform the last interviews.

The heads of the RU and ICU played a key role in the recruitment process of the physicians as well as the nurses. They acted as gatekeepers during the recruitment process, and provided the names of physicians and nurses who were thought to be interested in participating. I then contacted the identified physicians and nurses by email. The email included information about the study and a consent form (Appendix 1). All of the invited physicians and nurses agreed to participate in the study.

Table 2 Composition of the focus groups Sub-study I

Focus group	1	2	3	4	Total
ICU Physicians	1	3	2	1	7
RU physicians	2	1	2	2	7
Total in each focus group	3	4	4	3	14

Table 3 Demographic data of the participants Sub-study I

	ICU physicians	RU physicians
Men (n=10)	6	4
Women (n=4)	1	3
Age M (minimum–maximum)	50.8 (41–67)	45.7 (34–60)
Experience in ICU / RU (years) M (minimum–maximum)	15.7 (3–32)	7.2 (2–14)

Table 4 Composition of the focus groups Sub-study II

Focus group	1	2	3	4	5	6	Total
Nurses ICU	2	3	2	3		2	12
Nurses RU	2	3	3	3	3		14
Total in each focus group	4	6	5	6	3	2	

Table 5 Demographic data of the participants Sub-study II:

	Nurses in ICU	Nurses in RU
Men (n=10)	0	2
Women (n=4)	12	12
Age M (minimum–maximum)	38 (31–55)	34 (25–47)
Experience in ICU / RU (years) M (minimum–maximum)	8 (1–14)	6 (9 months–15 years)

Data collection focus group interviews

The semi-structured interview guides were planned, yet flexible, in order to use the knowledge-producing potential of dialogue (106). Interview questions were derived from own work experience, a review of literature and the experience from the pilot interview.

Studies have demonstrated that health care personnel are happy to talk about ethically difficult situations, although they seem to have difficulty actually explaining their ethical values and ways of ethical reflection. People live and act out their morals, without necessarily being explicitly aware of their values. To gain access to the morals of physicians and nurses, the best way is to ask them to tell stories (124). We presumed that the open-ended questions would possibly uncover new knowledge about the decision-making process, in which the values and considerations of the healthcare personnel would be made visible. Since the physicians have the legal authority to make decisions,(5) the topics were related to their clinical experiences in making decisions regarding initiating, continuing or discounting NIV or MV. For the nurses, the topics were related to their involvement in the decision-making regarding initiating, continuing or discounting NIV or MV (Appendices 2, 3).

The data collection took place from November 2012 to May 2013 (a rate of one to two per month). The interviews with both the physicians and the nurses were conducted in a quiet room at the hospitals, which ensured privacy. The participants had chosen the place and the time, in order to feel more empowered in their interaction with the researcher (125).

Each session lasted from fifty minutes to one hour and fifty minutes.

In eight of ten, my supervisor (KH) was the assistant under the interviews. In two of the interviews, my supervisor considered herself as partial, as she knew the participants. I was the moderator in all of the ten focus group interviews (four with physicians and six with nurses).

We sought to create a friendly environment with the intention of allowing spontaneous statements and personal experiences to emerge (121). At the beginning of each interview, I introduced myself, as a researcher, and as a nurse with clinical experience. The point of mentioning this was to tell the participants that the themes were in one way known and experienced by me as a researcher. Then I introduced the themes for discussion, the aims of the study and how focus group interviews are implemented. The role of the moderator was to ensure that all the participants got a chance to voice their opinions (118). In line with Brinkmann and Kvale's principles of qualitative interviewing, (106) I

was attentive to the participants' stories and sensitive to surprises or changes during the interviews that might challenge my preconceptions. During all the interviews, there was an interaction between questions and answers (e.g. 'What is your experience? Can you describe...?') The participants were also encouraged to elaborate their statements, using pauses and probes such as 'Would you give an example?'

As seen from tables 2 and 4, the size of the groups was relatively small, and varied from two to six participants. Small and homogenous groups may have encouraged an open atmosphere (126). The participants were all very engaged in the themes, and as far as we could see, all of them got opportunities to communicate what they found important to discuss. At the end of each session, a brief summary of the discussion was offered, to which the participants were invited to comment.

The interviews were audiotaped and then transcribed verbatim after each interview. Field notes regarding participant interactions were added.

The individual interviews (Paper III)

The interview seeks to understand the meaning of central themes related to the participants' lifeworld, the lived everyday world as related to being seriously ill; and to determine the extent to which they were involved in relevant decision-making processes. The qualitative interviewer encourages the participants to describe as precisely as possible what the experience and feel and how they act. The focus is on nuanced descriptions that depict the qualitative diversity, the many differences and varieties of a phenomenon, rather than ending up with fixed categorizations. The individual interview is an inter-view where knowledge is constructed in inter-action between two people (106). We chose individual in-depth interviews as the best method to interview the late stage COPD patients. The reason for this was that many of the themes in the interviews were highly personal and sensitive. Moreover, the participants' poor physical condition made it hard for them to leave their homes.

Sampling and recruitment of patients

In this study, we wanted to explore how older patients with late-stage COPD experience being seriously ill and perceived their involvement in decision-making regarding NIV or MV. The inclusion criteria were older patients (≥ 64 years old) with late-stage COPD (GOLD III-IV), comorbidities, and episodes of serious exacerbation that resulted in hospitalization and MV and/or NIV- treatment at least once

during the previous year (Table 6). All participants could write and speak Norwegian and were all in possession of their cognitive faculties. None of participants were hospitalized during the interviews.

Nurses who worked in one university hospital and two district hospitals in outpatient clinics recruited the twelve patients and made the initial contact. They asked the patients if they would like to participate in the study, and they gave them written and oral information about what it meant to participate in the interviews. One week after the initial contact was made, I contacted those patients who had given their willingness to participate in the study and provided them with further details about the project. All the invited patients agreed to take part in the study. Voluntary informed consent was obtained from all patients prior to data collection (Appendix 4).

Table 6. Demographic and medical characteristics of the participants.

Characteristics	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Age	63	87	71	65	64	67	68	70	74	82	64	67
Gender	F	F	M	F	F	M	M	M	M	F	F	F
Marital status	MA	D	W	MA	MA	D	D	MA	L.A	W	D	D
Disease years	7	5	15	10	8	5	10	10	14	20	15	15
NIV/MV last year	M	N	M	M	M	N	N	N	N	N	M	M
Fixed O ₂	O ₂	O ₂	-	O ₂	O ₂	O ₂	-	O ₂		O ₂	-	O ₂
Hospitalized last year	2	2	5	12	5	7	10	2	5	3	4	5

Note: P=patients, F= female, M= male, MA= married, D= divorce, LA= living alone, and

W= widow/widower.

Data collection individual interviews

A semi-structured interview guide was conducted. The topics in the individual interviews were: the participants' experiences of (1) being in late stage COPD and (2) their involvement in decision making regarding NIV and MV and EOLC (Appendix 5).

Data were collected from January to June 2013, either in the participant's home ($n=10$) or in a nursing home ($n=2$). Visiting the participants in their homes, appeared to suit most interviewees (107). I conducted all twelve interviews face-to face.

I started the interviews with a presentation of myself, not only as a researcher, but also as a nurse. The point of this was to help the participants to feel comfortable and confident about my competence in understanding their condition and the need for breaks during the interviews. Some of the participants needed a break during the interviews, for example, for crying, coughing or changing position from chair to bed.

After the introduction, I asked the participants for some background information (Appendix 5) These initial questions often led to further stories about how they felt about their illness, and their involvement in decision-making processes. I followed up with questions in a reflective way, which encouraged the participants to share their stories (e.g. whom do you talk to about your worries regarding the future? How do you feel about getting involved in the decision about your treatment in the future?).

Through the interview, I wanted to achieve an understanding of the situation from the participants' points of view, to unfold the meaning of their experiences and to uncover their lived world. The interviewer registers and interprets the meanings of what was said as well as how it was said. I found the participants' homes to be suitable to provide me a deeper insight and understanding of how they live their daily lives. In this way, I got the opportunity to observe how they manage to deal with their physical impairment and how they struggle with breathlessness in their own environment. Commenting on these visual signs made the interview situations more natural and smoother, for example: "I observe that you hold your hand on your back, does that mean that you have pain?"

The interviews differed, both in length and in content, since some participants talked more freely and openly about their experiences, while others gave only short answers to the questions asked. During the interviews, I tried to pay attention to ethical transgressions of the participants' boundaries. The

researcher was aware of the participants' willingness or reluctance to talk about the themes. Some of the themes were of sensitive nature, but most of the participants did not seem to find it difficult to share the experiences. Sometimes I became very touched both by the story and the powerful way it was told. I believe this was visible, through my active listening and body language, but it never came to a stage where these emotions took over.

I made notes immediately after the interviews, describing the context and atmosphere, and my reflections on the conversation and any aspect raised after the voice recorder was switched off. All the interviews were audiotaped, and then transcribed verbatim and de-identified.

The transcripts for both the focus group interviews and the individual interviews were written as faithfully as possible. Pauses, laughter, crying and other wordless expressions of feelings were registered in the text. I decide to present all the text in standard Norwegian language. An experienced typist transcribed seven out of twenty-one interviews. I read these texts carefully while listening to the audio files.

Data analysis

I have chosen to present the analysis of the focus group interviews and the individual interviews in the same subsection. The approaches to the two types of data collection had much in common and the process of analysis is basically the same (127).

The aim of the interviews and the interpretation was to get as close as possible to the interviewees' experience and to formulate a coherent and theoretically third person perspective on the experience. To understand the lifeworld and the participants' subjective experiences, we had to interpret these experiences within a larger framework. This approach acknowledges the active role of the researcher in the research process.

The analysis is a cyclical process as well as a reflexive activity, starting when collecting the data, the writing of summaries after the interviews and by listening to and transcribing the interviews. In the hermeneutic tradition, this circularity is viewed as a positive opportunity for gaining new knowledge. However, in the hermeneutic spiral, the understanding cannot be final (128). The analysis will only reflect a part of the complex themes the participants shared in the interviews.

The data generated in these sub-studies were analysed in three interpretative contexts described by Kvale and Brinkmann (106): self-understanding, critical understanding or common sense level, and theoretical level (Table 7). These three levels addressed the meaning of the text in three different interpretational contexts, but did not represent consecutive steps; rather the researcher switched back and forth. The analysis was conducted in cooperation with all four authors of the papers. Two of the authors (HJ and KH) read all the transcripts and the other two authors (PN and VD) read parts of the transcripts. In reading the transcripts and the field notes several times, we got a sense of the whole before we discussed and agreed upon some main themes.

In the self-understanding context, the researcher tries to capture what the participants understand to be the meaning of their statements. At this stage, the phenomenological approaches were most evident as the material was more open to a first impression. The researcher tries to capture what the participants understand to be the meaning of their statements. To capture these perceptions, we coded the data so that the texts' meaning could be seen more clearly. The coding was data-driven, in which the text is reorganized and organized by the way of codes developed from the data itself in an inductive process (106). An early stage of analysis was listening and re-listening to audio files. In listening to the tone of the participants' voice, sighing, pausing, silence and sometimes crying gave supplemental information to what the participants said. Based on these themes, the data were coded manually, using colors.

In the critical common-sense understanding context, the researcher goes beyond what is actually expressed and the meaning of what is said, as the researcher asks questions of the data and interprets it. The analysis thus includes a wider frame of understanding than that of the participants themselves. In this way, the coded data was transformed into meaningful data. All the coded units related to a particular code were presented together in order to explore and interpret the meaning in each code set. The main codes were retrieved, split into sub-codes, spliced and linked together and summaries were made (106).

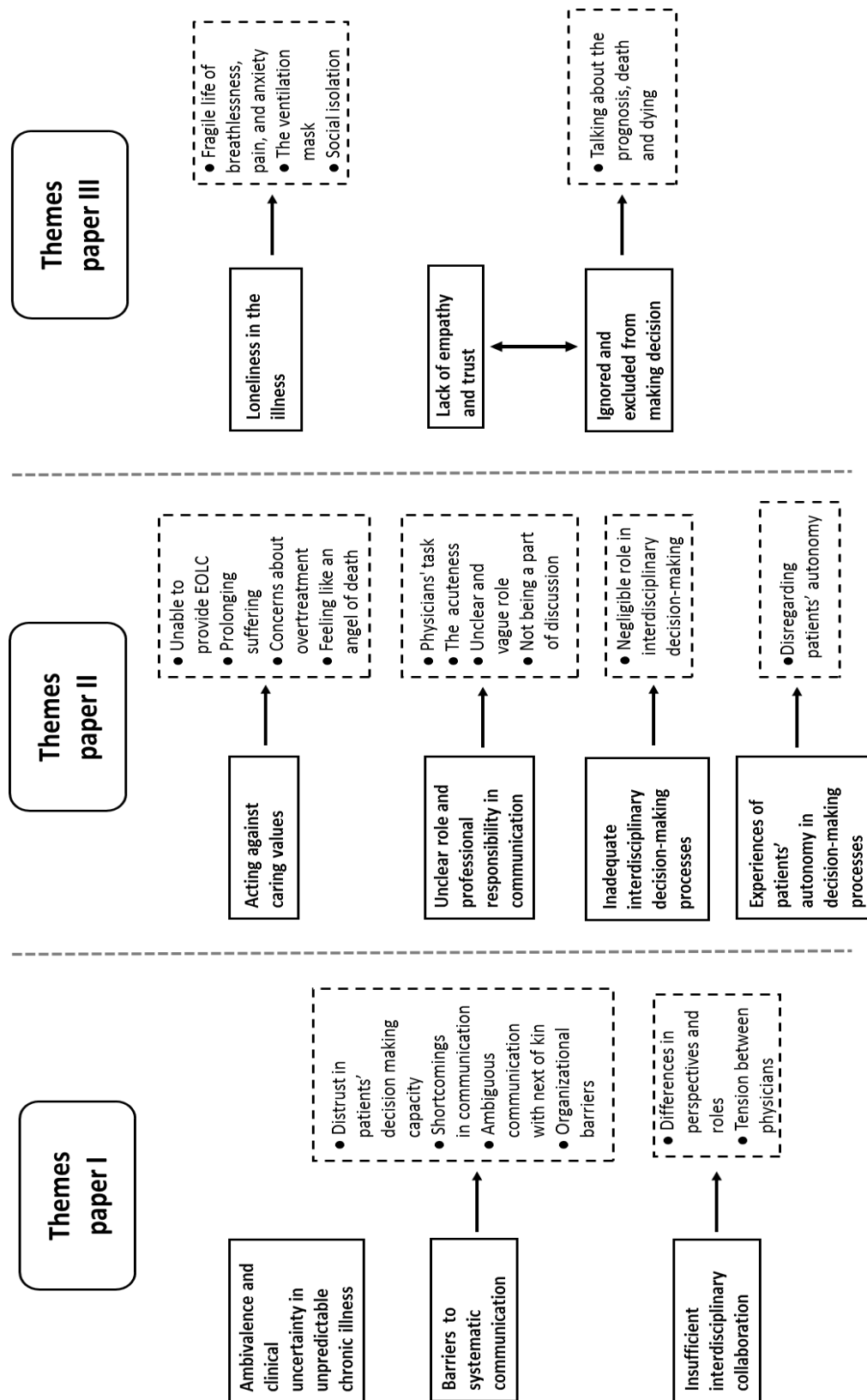
In the context of theoretical understanding, a theoretical framework and summary of existing research relevant to the study (Chapters 1 and 2) were applied to understand and interpret the theoretical meaning of the data in order to generate theoretical themes (106). In this context, the researcher stepped back, considered what the analysed data meant, and assessed their implications for the questions at hand. The Norwegian National Professional Guidelines,(6 , 7) international guidelines, (11) and the regulations in the Patients' Rights Act (5) were taken into consideration. Furthermore, notions of autonomy and care

provided key perspectives, in combination with research and literature on decision-making, limiting treatment, and patient's experiences of being in late-stage of COPD. Summaries and theoretical themes were generated, which were later discussed with the co-authors. The original transcripts were also reread to validate whether the theoretical themes still reflected the original contexts appropriately (129).

Table 7. Illustrations of how data were structured into the three interpretative contexts

Self-understanding	Common sense level	Theoretical level
<p>The individual interview</p> <p>Patients:</p> <p>The doctor told me subsequently that I would not receive that lifesaving help again. I am so afraid that they will let me die next time I have an exacerbation. I know there will be a next time and then I will not receive the treatment I need to survive. I still want to live a little longer”</p>	<p>Ignored and excluded from making decision about care and treatment.</p>	<p>Trust related to partake in the decision-making.</p> <p>Trust related to information regarding relief of ailments.</p>
<p>The focus-group interview</p> <p>Physicians:</p> <p>Some COPD patients do not know that they are dying from it. These patients are not exactly academics. Perhaps they can live in ignorant bliss.</p>	<p>Barriers to systematic communication</p>	<p>Disregarding the patients’ autonomy</p>
<p>The focus-group interview</p> <p>Nurses:</p> <p>We observe all the suffering to a much greater extent than the physicians do. That makes it hard to be a nurse. Sometimes the patient is allowed to die, but not often.</p>	<p>Prolonging suffering rather than protect from harm.</p>	<p>Operating within a cure-directed treatment culture wherein the nurses were unable to stand up for the caring values</p>

Figure 2. Main themes and sub-themes in the three sub- studies



Ethical considerations

Research on human beings demands careful considerations for their security, anonymity and welfare, in order not to insult individuals or expose them to unnecessary harm (89).

Permission to conduct the interviews, as well as to collect and store data, was obtained both from the institutional review boards of the participating hospitals and the Regional Committee for Medical Research Ethics (REK) (ref. 2012/618). To ensure anonymity, the analyses were carried out using de-identified transcripts. De-identifying the prints meant the removing of the names of the participants, their families, friends, names of hospitals, names of places and other information that could identify the participants. The co-authors read the written interviews after they were de-identified. All information was stored confidentially, in locked, specially designed cabinets at Oslo and Akershus University College(HIOA). Only the researcher and an experienced typist who was well informed regarding the ensuring of anonymity listened to the recordings.

Ethical reflection on qualitative methodology

When researching human beings who are concerned with how their lives and experiences are described, conceptualized and analysed, it is impossible to separate completely the values and the facts, the ethical issues and the scientific issues. Rather than seeing the ethical issues as settled, they might be described as fields of uncertainty (106). Qualitative research can create a tension between the wish to obtain deep knowledge and the risk of transgressing on the person (130). In the focus-group interviews with the healthcare personnel, we consider the risk of transgressing on the participants as small. In the in-depth interviews on the other hand, it was important to gain a balance between the urge to get valuable knowledge and care for the patients' defenses against vulnerabilities. This demands that the researcher shows sensitivity for the extent to which they wanted to share their lived experiences. As a researcher, I tried to meet the participants with empathy and sensitivity. I informed the participants about their right to decide what they wanted to share in the interviews, and that my questions could be experienced as too personal or perhaps for some even invasive. None of the participants stopped the questions or failed to answer, but two of the participant gave very short answers like *yes* or *no*. The reason for the short answers might have been the participant's unwillingness to share experiences or an attitude that the questions were too private.

The qualitative interview is an interaction between researcher and the participant; however, the interview entails an asymmetrical power relation (130). The researcher has both professional knowledge and scientific competence, the power to determine the interview topics, poses the questions and decides which answers to follow up (106). The location of the individual interviews was the participants' home. Interviews conducted in participants' homes might be important as a strategy for disrupting the classical power hierarchies between researcher and participant as the patient will often feel more empowered in this setting (125).

At the time the interviews were conducted, the participants were characterized by severe illness. Because of their severe illness, they were in circumstances that made them particularly vulnerable. However, they did not have any difficulty giving free and informed consent or make personal decisions. We regarded the potential harm in this study to be minimal. The direct benefit related to this interview could be that the participants gained the opportunity to give a voice to experiences, thoughts and beliefs. The value of being heard might be empowering. Some of the participants told me after the interviews that they felt relieved and confirmed to have somebody listening to their experiences. However, some of the participants said it was hard to share feelings of loneliness and anxiety. Before the interviews, I had made an appointment with the nurses who knew the participants, so they could call them if necessary. I informed the participants about this option before and at the end of each interview, but I do not know if anybody needed that contact.

Methodological considerations and limitations

Brinkmann and Kvale (106) emphasize that it is particularly important to consider quality criteria relating to a study's reliability, validity, and the generalization of the findings. There is an ongoing discussion in the qualitative research tradition about how to use these concepts which are traditionally used in quantitative research. Nevertheless, these concepts are well known in relation to the evaluation of research, and Brinkmann argues for their relevance in a reconceptualised form (106). However I will start this chapter with a brief description of the of relationship between the researcher and the researcher's work, also called reflexivity (131).

Reflexivity

During the time I spent working on the thesis, a dynamic interchange of knowledge, understanding and perception of the themes was a part of the analytic process. I started by interviewing physicians (Sub-

study I) and nurses (Sub-study II) and finally patients. The interview process took place over a relatively short period of time. During this process, I did interviews, transcribed them and analysed the data. I got a clear picture of the healthcare personnel's experiences before I started the interviews with the participating patients. This knowledge has colored both the questions I asked in the interviews and my interpretations of the participants' responses, especially in writing Paper III. While working on this research project, I saw the obituaries of several of the participating patients in the newspaper. The fact that some of the participants were so close to death, underlines the importance of conversation about what patients in the late-stage of COPD actually want of treatment and care.

Throughout the research process, I have tried to remain critically reflexive with regard to personal experiences that might have influenced the analysis. This reflection has matured my position as a researcher and my concern regarding my own self-representation, skills and trust in the processes of creating the empirical material. I consider my attitudes and preconceptions to be a part of my own awareness of my role as a researcher. I have taken a great care to maintain reflexivity in all my interactions with participants in the interview situations.

Reliability of the sub-studies

In the words of Brinkmann and Kvale (106 p.281) 'reliability pertains to the consistency and trustworthiness of research findings; it is often treated in relation to the issue of whether a finding is reproducible at other times and by other researchers'. In qualitative research, the researcher serves as an instrument in both generating and analysing the data. Two researchers studying the same phenomena might not share either the same perspectives or the same interpretations. They should however, be able to understand how they arrived at their respective interpretations and should be the subject of reflection and transparency (118). Throughout this study, it has been important for me to justify my choices, procedures and methods, as well as how the study was implemented to achieve transparency in both the papers and the thesis.

The researcher's preconceptions and theoretical perspectives are considered to have influence throughout the entire qualitative research process and are outlined in chapter 4 and 5. I have systematically attempted to recognize these preconceptions, as recommended for qualitative research (106). However, my preconceptions are sometimes difficult to recognize because they are both a conscious and an unconscious part of me as a person.

The individual interviews

The interviews were conducted with the aid of an interview guide containing semi-structured questions reflecting the aims of the study. I developed the interview guide in cooperation with my supervisor. The guide was rooted in theory and previous studies towards the same themes. A limitation was that we did not test the interview guide in a pilot study.

Brinkmann and Kvale write that interviewer reliability is particularly related to leading questions (106). I tried to avoid leading questions, but in two interviews especially, I experienced that this was difficult because those participants gave short, often single word answers such as *yes* or *no*. I did not want to push these participants to elaborate the themes in these cases, but I experienced these interviews as challenging.

The focus group interviews

In order to ensure appropriate and understandable questions for discussion, the interview guide was tested in a pilot study.

During the focus group interviews, the moderator encouraged the participants to follow up and clarify the meaning of relevant topics being discussed. Both the moderator and the assistant asked follow-up questions, like ‘*Can you tell more about what happens?*’

The fact that I am a nurse and that I informed the participants about this fact, may have influenced the focus group discussions. Subsequently, in analysing the interviews, I recognized that it was easier for me to ask follow up questions during the interviews with the nurses than with the physicians. This may have led to more rich data from the interviews with the nurses.

The transcripts for both the individual and the focus group interviews were carefully checked for errors by listening to the tapes again in their entirety. In the focus group interviews, we also attempt to connect the reader to the transcripts through well-chosen quotations of participants’ statements, thereby improving reliability (123). The reliability of both the individual interviews and the focus group interviews was strengthened by the fact that all the authors were involved in the analysis, individually and together.

Validity of the sub-studies

Validity refers to whether a study investigates what is intended to be investigated. According to Brinkmann and Kvale, this rests on quality of the researcher's craftsmanship. Researchers are encouraged to continually ask questions (what and why) and theoretically interpret their findings throughout the entire research process (106). By using different data collection methods and different groups of participants addressing the same phenomena, we improved the quality of data and our depth of understanding, thereby contributing to the overall goal of triangulating the findings (132). The validity of the findings was strengthened by the fact that similar results were shown in the focus group interviews and in the individual interviews. The responses from healthcare personnel both when we presented the study at conferences and in the papers, showed that they recognized both the themes and the experiences that were elucidated. This may strengthen the communicative validity of the studies.

Limitation in sampling and inclusion

This research has only shed light on the perspectives of patients and healthcare personnel working in hospitals. Interviews with relatives and general practitioners might have added valuable knowledge to the study, since these people often are involved in information exchange and the decision-making process. Their experiences may have provided an outside perspective that could have situated patients' experiences of illness in a broader context.

The sampling of participants in both the individual interviews and the focus-group interviews with the physicians might be too homogeneous. The participants in the individual interviews were recruited from only three hospitals in the eastern part of Norway. There may be different care and treatment cultures in other places in the country. On the other hand, the hospitals represented both urban and rural populations. Additionally, the hospitals are positioned such that they serve people of different socioeconomic conditions.

It proved to be a little more difficult to recruit physicians than nurses. This may have been because of their heavy workload, or perhaps lack of interest in the topic or the fact that I was a researcher with a nursing background. The participating physicians were therefore perhaps more conscious about ethically challenging clinical practice than their colleagues who did not participate. This may be a limitation of the study.

The sample with nurses and physicians was different with respect to gender. Ten of the participating physicians were men and four were women. In the group of nurse, there were two men and twenty-four women. Traditionally, women tend to speak more easily about emotions. Gender differences were not a primary interest and the sample is too small to make any conclusion related to the gender differences.

Reflections on the validity of data collection and analysis

The choice of method for collection of data will have an impact on validity (117). We wanted to get close to the participants' experiences and grasp the meaning of those experiences.

The individual interviews

During the individual interviews, some participants talked for the first time about their experiences of being seriously ill. Talking about a theme for the first time might reinforce a person's sense of deprivation regarding being able to share their thoughts, and this might increase their desire to receive comfort and care. Some of the participants cried and expressed feelings of grief and loss of hope. In these situations, I chose to stop asking to support and comfort the participants. However, we continued the interviews after a break. I was often moved both by participants' stories and by their willingness to share. A central discussion related to qualitative methodology is the balance between personal proximity to and distance from themes in the research (118).

The research interview is a specific professional conversation, which typically involves a clear power asymmetry between the researcher and the subject (106). It is difficult to know if some of the participants adjusted their answers to reflect what they thought I wanted them to say. To test my understanding of the meaning of the participants' statements I asked them questions such as: 'Do I understand you right when you express yourself?' This is an approved strategy for ensuring validity in qualitative research (106). However, it may be difficult to fully guarantee that the researcher and the participants have the same understanding of the matter in question.

The focus group interviews

A limitation may be that group norms, such as conformity or nonconformity, affect what some of the participants' say and how they say it (123). To preserve individual experiences in the group context, we arranged small groups (two to six participants) and gave them relatively high degree of structure to ensure that everyone had the opportunity to speak. We tried to create an open atmosphere during the

interviews, thereby allowing unanticipated statements and personal experiences to emerge. A limitation, however, was that in each group one or two of the participants talked more than the others did.

We decided to interview physicians and nurses in separate groups, in order to ensure that the hierarchical relationship did not influence what participants would share. While this ensured that the participants in each group had a common frame of references, a greater variety and richness of collected data may have been achieved by including participants across professions.

Interaction is the key to this interviewing method, giving it a high level of face validity because what participants say can be confirmed, reinforced or contradicted within the group discussion (121). However, focus group studies are often criticized for not taking group interactions into consideration in the analysis (127). For example, Morgan states that even though group interactions are essential to producing focus group data, whether the group interaction itself constitutes data depends upon the aims of the research (133). We did not consider the interactions as an aim and this was therefore not included in the analysis. However, we showed the discussion/interaction between the participants by including quotations from two different participants in Papers I and II.

To ensure that we understood the content of what was said, the assistant offered a brief summary of the initial impressions from the discussions, on which the participants were invited to comment.

Analytic approach in both individual interviews and focus group

In the analytic process questions were raised regarding what to include and what to exclude when proceeding further with the analysis following coding(106). In the study, I used only small excerpts from the participants' stories. The extensive references to text elements from the interviews constitute a risk of bias in the presentation of the findings. The co-authors read all the transcript data material to ensure that the data presented the participants' experiences.

In selecting the data, we used the research questions. I tried to remain open-minded or an 'informed outsider' during the coding, although my own preconceptions and the aim of the in research all likely influenced the choice of themes, concepts, quotes and theory further along the processes. Being an 'informed outsider' means taking a position as a researcher that affords a productive distance, making it possible to recognize, see and understand phenomena that the participants take for granted (134).

A limitation of both the focus-group interviews and the individual groups was that the data analysis was not given back to the participants for ‘member checking’ of its validity or plausibility as an explanation of what was said. I chose not to do so for practical reasons. I considered the participating patients’ health situation as instable and vulnerable. In my opinion, a member check would probably have been more stressful for them than useful. When it came to focus group interviews, I considered the heavy workload in the acute wards to be a reason not to ask the participants for member checks. However, in a phenomenological approach, another researcher or research participants might produce a another version, but that in itself does not render the first version invalid – it merely adds another plausible description for readers to examine (106).

Generalization of the findings

The purpose of this study has not been to generate statistical generalization on the basis of a large population, but to gain knowledge of arguments, various assessments, considerations, values and power relation that could elucidate the decision-making process for patients’ with late stage COPD.

In qualitative research, the generalizing of interests is whether knowledge produced in a specific interview situation may be transferred to other relevant situations (106). Analytical generalization, as described by Brinkmann and Kvale, involves a reasoned judgement about the extent to which the findings of one study can be used as a guide to what might occur in another situation, and is based on an analysis of the similarities and differences between the two situations (106). To increase the transferability of the findings in the studies, a description of the contextual background is given including as demographics of the participants and the study settings (114). This enables the reader to evaluate which situations the findings might provide valid information for and thereby the transferability of the findings (106).

6 Results and discussion

Presentation of main findings in Papers I-III (figure 2)

The principal findings running through all three papers are:

1. Patients with severe COPD are rarely included in decisions about possible treatment options at the end of their lives.
2. Physicians and nurses have different motives for excluding patients with late-stage COPD from decisions regarding their treatment.

Most of the participating patients wanted to be included in discussions regarding NIV or MV treatment, but none of them had experienced that they were included in the decision-making process. These patients described a fragile and burdensome life frequently interrupted by unpredictable and frightening exacerbations of their illness.

Paper I: Consideration and values in decision making regarding mechanical ventilation for older patients with severe to very severe COPD

The purpose of the study was to investigate the physicians' considerations and values that influences physicians' decision-making regarding NIV and MV in older patients (≥ 65 years old) with late-stage COPD. Furthermore, it aimed to elucidate how physicians involve their patients in the decision-making process. The study aims were achieved by interviewing 14 physicians (7 ICU physicians and 7 RU physicians) using four focus groups for data collection.

The three main themes in this Paper reflect the challenges the physicians experienced during the decision-making process regarding NIV or MV. The first theme, *ambivalence and clinical uncertainty in unpredictable chronic illness*, was based on the physicians' reported difficulties in predicting prognosis for severely ill patients with COPD. Uncertainty arises because prognosis for the severely ill patients with COPD is difficult to predict. The uncertainty alone was frequently an argument for both initiating and continuing NIV or MV.

For the second main-theme *barriers to systematic communication*, the interviews revealed that physicians had no systematic routines for communication with their patients about treatment options,

prognosis, and life expectancy or EOL issues. Patients were very rarely involved in the decision-making process. The subtopics underline the barriers that contribute to the lack of communication with patients and their next of kin. The first subtopic *distrust and inconsistency in the patient's decision-making capacity*, referred to the physicians' doubts about whether conversations regarding prognosis were in the best interests of their patients. Because patients rarely requested such conversations, their requests could appear inconstant and conflicting and their ability to understand their own situation was poor. The second subtopic, *shortcomings in communication*, was based on physicians' reflections on their perceived shortcomings when they could no longer offer active treatment. Some of the participants described situations where they felt lonely and lacked support from colleagues.

The third subtopic *ambiguous communication with next of kin*, underscored the physicians' perceptions regarding next of kin as both helpful and demanding. Some physicians described a feeling of powerlessness when confronted with unrealistic expectations on the part of next of kin.

The fourth subtopic *organizational barriers to involving patients in decision-making*, referred to the system at the hospitals as a barrier to good communication, which additionally complicated continuity in treatment and care throughout the patients' hospital stay. The fact that it was often the least experienced physicians who first met the patient in acute situations, could easily lead to both under- and overtreatment.

The third main theme *insufficient interdisciplinary collaboration*, referred to the physicians' considerations about being sovereign when making medical decisions. They rarely involved the nurses in decision-making regarding MV or NIV.

The subtopic *differences in perspectives and roles* reflected that there were also different attitudes and opinions regarding treatment benefits of MV or NIV for the patients with late- stage COPD among physicians.

These differences in roles and perspectives lead to the second subtopic called *tension between ICU physicians and RU physicians*. Although the physicians reported tensions in their discussions about the intensity of treatment, they did not describe this as a conflict. The ICU physicians were actually more restrictive than the RU physicians when it came to deciding whether the patients with late-stage COPD should be offered a MV treatment. The ICU physicians argued that the weaning process was sometimes very difficult or even impossible for many of those patients.

In conclusion, this paper implies that decision-making processes related to whether older patients with severe COPD should be treated with NIV or MV were both medically and ethically challenging for physicians. Decision-making in this context seemed to be mainly driven by a paternalistic attitude, since the responsible physicians interviewed in the study, in general, made such decisions without involving either the patients, their next of kin or the responsible nurses.

Paper II: Nurses' role and care practices in decision-making regarding artificial ventilation in late-stage pulmonary disease

The purpose of the study was to investigate how nurses experienced their own role and care practice in decision-making processes regarding NIV or MV in later stages of COPD, and how they considered the patients' role in these processes. A qualitative approach was applied, with six focus group interviews of 12 ICU nurses and 14 nurses working in RU (n=26).

Three main themes were identified within the results. The first main theme, *acting against caring values*, described the nurses' experiences of caring for the patients with late-stage COPD. The nurses described the patients as very vulnerable and suffering greatly. The dilemmas described by nurses were related to their experiences of being a part of a biomedical treatment culture that was not focusing properly on the patients' need for good and compassionate care in the late stages of COPD.

For the first subtheme, *unable to provide EOLC* the nurses reported that, in their opinion COPD patients often received aggressive treatment until death rather than compassionate EOLC. The nurses expressed concerns about the lack of systematic and appropriate EOLC for these patients.

In the second subtheme, *prolonging suffering rather than protecting from harm*, the nurses expressed their worries regarding the extensive use of NIV or/and MV during the severest stage of the disease, which in many cases implied an obvious risk of prolonged harm, rather than being beneficial for the patients.

The third subtheme, *concerns about overtreatment*, illustrated the nurses' expressed concerns about implementing the physicians' decision when they themselves felt that aggressive treatment was the wrong path. The decision often caused an ethical dilemma for the nurses because the physicians focus was life-preserving treatment, which in many cases extended patients' suffering according to the nurses.

The fourth subtheme, *feeling like an 'angel of death'*, referred to the nurses experiences of being accused of bothering the physicians by nagging if they raised questions about futility, overtreatment and prolonged suffering.

The second main theme *unclear roles and professional responsibility in patient communication regarding MV*, implied that the nurses experienced that they did not have a clear and respected role in the interdisciplinary discussion regarding what would be the right treatment during the late-stage COPD. The subthemes illustrated the experienced reasons for not participating in the decision-making process.

Subtheme one *negligible role in interdisciplinary decision-making* described the nurses experiences of not being invited to participate or included in discussions about decision-making related to treatment options. In their experience, the physicians did not include them and were not paying any interest or attention to their opinion or knowledge about the patient. There was minimal interdisciplinary conversation it and primarily involved one-way information about treatment from the physicians. The nurses also experienced disagreements between RU physicians and ICU physicians regarding the intensity of treatment and felt like the patients' suffering was prolonged due to such disagreements.

The third main theme *patients' autonomy in decision-making concerning MV* was lacking according to the nurses. Communication with patients regarding their preferences and thoughts about NIV or/ and MV was not structured, planned or systematized. One the one hand, the nurses were concerned about this, but on other hand, none of them considered this type of conversation with the patient to be one of their responsibilities. In conclusion, as elucidated in the second main theme, the nurses felt that they had no clear role in treatment and/or EOLC communication with the patients.

The subtheme *disregarding patients' autonomy*, referred to the nurses' experienced dilemma of rarely knowing their patients' preferences regarding NIV or MV. Even, when their patients' preferences were known, the nurses experienced that these preferences were ignored and not documented in the patient's medical record.

In conclusion, the nurses found themselves operating within a cure-oriented biomedical treatment culture wherein they were unable to stand up for the caring values. To be able to advocate for the patients' right and their own right, to be included in decision-making processes, the results implied that the nurses needed a stronger awareness of their legal and ethical responsibility as nurses. This requires

strong professional identity, courage, willingness and enthusiasm on the part of the nurses, as well as clear leadership providing an interdisciplinary culture and a culture that ensures patient involvement.

Paper III: Older patients with late-stage COPD: their illness experiences and involvement in decision-making regarding mechanical ventilation and noninvasive ventilation

The aim of this paper was twofold: first, it aimed to understand, from the perspective of the patients, their role in decision-making processes regarding NIV and / or MV in late-stage COPD. Second, it aimed to gain a wider understanding of these patients' experiences of being seriously ill with COPD. In order to contribute to a wider understanding of these patients' assessments about being involved in decision-making processes, we found it necessary to start with an exploration of the patients' experiences of being seriously ill. Individual interviews with twelve patients with severe COPD (GOLD III-IV) were conducted.

There were three main themes reflecting both the patients' experiences related to the being seriously ill and their patients' experiences related to their involvement in the decision-making process regarding MV or /and NIV.

The first theme, *loneliness in the illness*, was based on patients' descriptions of feeling lonely and socially isolated, caused by the disease progression.

The first subtheme, *fragile life of breathlessness, pain and anxiety*, described patients' feelings of being fragile and vulnerable. The impact of breathlessness and the unpredictable episodes of exacerbations, were significant and pervaded daily life. The feelings of anxiety, and sometimes panic when they experienced the breathlessness reinforced each other and led to a vicious cycle wherein the patients felt they were losing control.

The next subtheme, *the ventilation mask- a bother and a lifebuoy*, was based on the participants' experiences of the ventilation mask as on the one hand tiresome and unpleasant, while on the other hand, they expressed an appreciation for having the opportunity to use the mask as a 'life-buoy'. The mask became a symbol of staying alive.

The third subtheme was *social isolation and loss of previous life*. The patients experienced that they had become isolated, partly due to practical challenges (use of fixed oxygen) and especially due to

breathlessness. They all experienced a grave deterioration of functional and social capacity, which decreased the everyday quality of life considerably.

The second main theme, *lack of empathy and trust*, described the patient's experiences of not being understood, met or comforted. These experiences implied that the patients did not initiate conversations with physicians or nurses, nor did the experience being included by either physicians or nurses in conversations about what they wanted in relation to treatment and care.

The last main theme, *ignored and excluded from making decisions about care and treatment*, was based on the patients' experiences of being told by the physicians what care and treatment they will receive without any additional discussion. The patients expressed that their care and treatment options depended on physicians' estimation of their conditions, without any actual involvement on their part.

The subtheme, *talking about the prognosis, death and dying*, illustrated that the patients' wanted more information and communication about existential worries, like prognosis and what death might be like. However, they felt ignored, not listened to, and talked to in a way that implied that they did not understand the message. Ten out of twelve of the patients interviewed wanted more information about their prognosis and wanted to participate in decisions regarding their own treatment and care. Two of the participants claimed that not knowing was for the best.

In conclusion, this study indicates that these patients were highly vulnerable and hence had complex needs regarding care and treatment in late stages of their illness. They had an unmet need for adequate information about diagnosis and prognosis. They were in great need of comforting, information and communication about existential worries. The patients needed predictability in terms of involvement, compassion, and care. Even though healthcare legislation and ethical codes, both for physicians and nurses include an obligation to ensure that the patients are informed, as well as ensuring that patients' values and preferences are taken into consideration in decision-making processes, the results from this study uncover that this is not the case in practice.

Discussion of findings

Findings from all three papers showed that older patients with late-stage COPD are not involved in the decision-making process regarding NIV and MV at any stage in the treatment process. This is evident from healthcare personnel perspectives as well as the patient experiences. Today, there is no international consensus regarding the kinds of decisions in which the patient ought to be involved (135). However, the Patient's right Act states that patients are entitled to have a say in the choice between available and medically sound methods of examination and treatment. Furthermore, the provision of services should as far as possible be designed in cooperation with the patient, and considerable weight should be given to patient's opinion. The patient should also be provided with information necessary to gain insight into their health condition as well as possible risks and adverse effects (5).

In the following chapter, I will discuss further possible reasons for the patients and nurses lack involvement in decision-making processes regarding NIV and /or MV.

I will first discuss the difficulties that the physicians experience with regard to the decision-making process. Then, I will discuss the physicians' possible rationales for not involving the patients in decision-making process. Next, I will discuss conflicting values among physicians and nurses and lack of interdisciplinary cooperation in the decision-making process.

From the patients' perspective, lack of involvement seemed to be closely connected to their experience of existential, physical and emotional challenges. The last part of this discussion will focus on issues regarding the patients' experiences that seem to have considerable impact on their involvement in decision-making regarding MV, NIV, and on their illness as a whole. I will refer to the three substudies in the following text as I, II, III.

The difficult decision

Findings in Paper I show that the physicians question whether it is in their patients' best interest to be involved in decision-making processes. They question whether such involvement really serves the complex needs of patients with late-stage COPD. Such questioning might be relevant because of both the acute situation and the unpredictable trajectory of the disease (22 , 136 , 137). Consequently, physicians reported of having an extremely difficult time predicating mortality in COPD patients (I). The decision to limit NIV or MV treatment for patients with a serious deterioration of COPD is also

quite often closely associated with EOLC and is therefore both medically and ethically complex decision. Findings show that the physicians were uncomfortable with the discussions that occurred in response to acute deterioration in clinical status, when immediate medical needs had to be weighed against the intentions and outcomes of treatment (I). Additionally, physicians are the ones who have to carry the burden of having the final responsibility for decision- making. In facing these difficulties, however, it is remarkable that instead of initiating shared decision- making, physicians seemed to act like sovereign decision-makers without involving either the patients or the nurses (I, II, III).

Findings elucidated that the physicians' intent to protect patients for information about their severe prognosis was justified by their desire to do well (beneficence) or at least, to do no harm (non-maleficence). These findings might reveal, however, that despite having such good intention, physicians seem to have paternalistic view of decision-making process. Beauchamp and Childress (10) write that in medical practice, physicians in particular are critical of the current emphasis on patient autonomy and patient involvement in decision-making. They question whether it really serves the complex needs of severely ill patients even though restrictions of patient involvement are comparable to hard paternalism. However, it may be argued that in an acute situation of respiratory insufficiency a paternalistic attitude is acceptable because the patient is in no condition to make decisions about treatment and care at this stage. This is, of course, true, but such argument primarily emphasizes the importance of involving patients in decision-making about their best interests on a more continuous basis, including before acute care is necessary. Nevertheless, I will argue that physicians and nurses are obliged to discuss these difficult questions about treatment and care with the patients during stable periods of the illness. Conversations during stable phases of the illness are necessary to give patients autonomy, to fulfill their best interests and to act according to legal commitment (54).

The paternalistic role taken by both ICU- and RU physicians in the decision-making process (I), has parallels to the model presented in an article by Emanuel and Emanuel (103). Emanuel and Emanuel proposed that the physician-patient relationship could be classified in four ideal groups 1) the paternalistic model, 2) the informative model 3) the interpretative model, and 4) the deliberative model (103). In the paternalistic model, the physician has a parental role and decides which treatment would be the best for his or her patient. The patient's autonomy is weak, while the physician is the only ones responsible for decision-making (103). The relationship between patient and physician in this model *assumes* that there are shared objective criteria that the physicians know in order to determine what is in the best interest of the patient. This assumption is consistent with our findings where the physicians did

not consider the patient's preferences and values as valuable for making good decisions about the patient's best interests. The physicians clearly saw themselves as the ones who knew what was best for their patients (I). This finding corresponds to findings in Borza's study (138), that show that an attitude that regards paternalism as justified beneficence still dominates parts of clinical medicine. According to this paternalistic model, the physicians can discern what is in the patient's best interests with limited patient participation (103). Physicians are undoubtedly the best qualified when it comes to medically knowledge, but that does not mean that they are the most competent when it comes to making ethically difficult decisions.

Rationales for not including the patients in decision-making processes

One rationale for not including patients in decision-making process was the physicians' experiences of patients not asking questions. Further, they did not believe in the patients' capacity to cope with information they expressed. This make them worry about the benefits of truth telling and some of the physicians considered this as the opposite of providing hope for their patients.

The physicians claimed that they preferred to withhold information due to their experiences of patients not asking questions about prognosis and treatment options or talking about their own preferences. This practice may be understood as a disclaimer of liability when placing the responsibility for receiving significant information solely on the patient. If it is so, such practice is in conflict with the Norwegian legislation that has mandated that the responsibility for giving information lies with the healthcare professionals (54).

Another rationale that seemed to influence both the RU- and the ICU physicians' choice to withhold information was their own evaluation of their patients' capacity to handle the information. This assessment was in particular related to their perceptions of their patients' health condition, age and education level. I will argue that this quote from Paper I shows a significant paternalistic attitude and usurps the patients' autonomy by restricting the information available: *'Some of the patients do not know they are dying from it. There is no point painting a darker picture, perhaps they can live in ignorant bliss?'*

In my opinion, such expression could imply that what information that was actually given depended on the physicians' personal judgement and attitude towards the patient and diagnosis. Information regarding the disease, prognosis and treatment options is a prerequisite for patients to make autonomous

decisions (54). Because the mortality rate is high, it is extremely important that patients with late-stage COPD receive information about their prognosis, even though the trajectory of the disease is unpredictable (11 , 139 , 140). Not to inform patients about a poor prognosis may deprive them of the possibility to deciding how they want the end of their life to be.

The physicians argued that even though the mortality rate was high in the late stages of COPD, they believed it would be too stressful for patients to be informed about the prognosis, paradoxically without asking them if they wanted information (I). This is in contrast to a study of terminally ill patients where only 1.9% perceived it as highly stressful to discuss end- of- life treatment (141). Additionally, it is well known that patients with COPD also want to partake in conversations about prognosis and disease progression (18 , 61 , 79 , 142).

Another rationale in decision-making was that the physicians' perceived a conflict of truth-telling versus preserving hope. Physicians said that they feared that discussions about prognosis, death and dying might jeopardize the hope that the patients bring to patient-physician relationship: As one physician said: *'I believe that it will do no good to speak about the fact that this disease will kill you'*. Studies have shown that although the patients with terminal illness value hope highly, they also want truthful information about their disease (143 , 144 , 145).

Consequences of withholding information may result in a practice where the physicians control truth-telling by not telling the whole truth. This may not mean that they advocate lying, but consider that not telling the whole truth is in the patient's best interests. Such an approach has direct implications when it comes to depriving patients of possible ways of understanding their disease and medical care and of autonomous choice.

Shortcomings in communication skills may be a reason for avoiding bringing up poor prognosis and withholding NIV and MV, and instead providing excessive treatment (I). In this perspective, it may be argued that to continuing medical treatment is considered less troublesome than having a difficult conversation with patients about treatment and care options at the end of their life (I). Another reason for not communicating about a patient's poor prognosis may be related to the lack of planned palliative care at end of life for the patients with late- stage COPD.

Revisiting the four traditional models of the patient-physician relationship Reach (146), proposes a model of care in chronic diseases based on patient education, pointing out that the ethical role of patient

education would be to make the deliberative model applicable to chronic care and, thus to give patients the opportunity to exercise autonomy in an ideal situation. In this regard, patient education is referred to as an ethical pathway that links three of four relationship models as follows: the physician first provides facts (the information model), helps the patients to elucidate their preferences (the interpretive model) and gives them opportunity to choose between their own preferences and those ones of the physician (the deliberative model) (146). This proposal is in line with Norwegian Directorate of Health guidelines, which recommend preparatory discussions in situations in which there is a risk of serious complications or at end of life (7). Additionally, the Norwegian legal framework explicitly highlights the patient's right to participate in choosing between various and medically sounds forms of treatment (54).

Even though it is problematic to generalize, these findings about paternalistic attitudes towards the involvement of patients with COPD, the tendency is that at least some parts of clinical medicine need to be more trained and conscious about the importance of communicating with patients about their future care. There are quite a lot of studies that will confirm this tendency (19 , 50 , 52 , 147 , 148).

Conflicting values and beliefs among nurses and physicians

In Paper II, the findings show that the nurses often experienced patients' suffering as a moral dilemma with relation to initiating or continuing MV or NIV, and/-or aggressive treatment. Additionally, the findings indicate that the nurses generally perceived their role and responsibilities with regard to decision-making processes to be unclear and unsatisfactory. As Paper I also highlights, the physicians rarely involved the nurses in the decision-making processes. Moreover, they rarely asked if the nurses knew anything significant about the patients' preferences.

In an attempt to understand these findings, I will discuss differences in physicians' and nurses' traditions and interdisciplinary disagreement about what is considered as the patient's best interests. Moreover, I will discuss the prevalence of proximity as a possible explanation for the nurses' repudiation of liability in decision-making processes.

Different traditions

Findings from Paper II show that the nurses experienced problems in clinical practice regarding conflicting values and divergent beliefs about the proper actions to take in complicated situations regarding these patients (II). The nurses experienced that they had an open internal dialogue among themselves about value perspectives related to what they considered to be in the patient's best interests at

the end of their life. However, the nurses missed interdisciplinary communication and explicit discussions among professionals (nurses and physicians) in situations with very complex clinical pictures (II). While the physicians confirmed the nurses' experiences of lack of interdisciplinary discussion, they unlike the nurses, did not consider this to be an important concern (I). They regarded discussions among colleagues of their own profession to be more imperative. In essence, the findings from both Papers I and II indicate that physicians seem to question each other, while nurses seem to question physicians. This lack of interdisciplinary communication is contrary to legal requirements, and, even more significantly, it obviously threatens patient autonomy since the nurses' voices rarely are heard in discussion regarding treatment and care (6 , 54 , 149).

The different historical and epistemological traditions followed by nurses and physicians may explain some of the challenges related to interdisciplinary agreement as to what the patient's best interests are. These epistemological traditions may bring about communicative misunderstandings, especially related to the use of concepts to describe a patient's condition.

While physicians traditionally emphasize biomedical knowledge (150), nurses' knowledge emphasize the patient's experiences of being ill (151). The nurses described patients' illness using words like suffering, undignified, lonely, and scared of dying. However, the nurses experienced that the physicians did not consider these descriptions of the patient's situation as either important or useful (II). The focus on objective criteria is vital for patients, but a strong focus on biomedical knowledge may lead to consideration of the patient's whole situation as less important. This is in line with other studies that show that physicians fail to take sufficient note of the value aspects of end-of-life decisions, focusing instead on discussions of medical parameters (152 , 153).

Knowledge of a patient's situation is complicated. A clinical situation contains both an objective and a subjective component. The body itself is expressive, but biomedical knowledge is decisive for understanding the physiological complexity in a given situation. When attempting to understand patients' experiences of being seriously ill and their body language, empathy is considered crucial. Empathy and moral sensitivity towards patients' suffering, as well as understanding of their subjective experiences of their illness, are important values in nursing (94). Empathy is emphasized in the International Council of Nurses' code of ethics and in the nurse education curriculum as valuable in the attempt to understand the complexity in patients' situations (149 , 151). Empathy may be understood as

the ability to identify and capture another person's feelings and subjective experiences and hence to understand that person in an appropriate way (154 , 155).

Recent studies carried out by physicians themselves have shown that medical students' empathy is often stunted during medical education, and empathy training is not sufficiently included in the core curriculum of medicine (150 , 156). That does not imply, however, that physicians do not feel any empathy towards their patients. Some amount of professional distance is sometimes needed to possess greater control in difficult and acute situations such as when making decisions about treatment for patients with severe COPD. However, this increased emotional distance may reduce empathy towards the patient. Nurses' empathy may be related to their continuous presence at the bedside or value orientations incurred by the epistemological traditions of nursing. Another reason for the openness and emphases of the subjective descriptions of the patients' situation may be related to the fact that nurses do not have the final responsibility for decisions and thereby feel more free to have a value-based and subjective opinion. Nevertheless, nurses should be more conscious about their own role in patient care as facilitators of clinical communication. The findings show that the nurses were too subservient and too reluctant to take clinical and ethical responsibility when they observe that communication was lacking. This is problematic. Both nurses and physicians have a clear responsibility to improve patient care. However, better interdisciplinary communication between these two groups could combine both perspectives for the benefits of the patients.

Lack of interdisciplinary discussions

In Paper II, nurses' dependence on and collaboration with physicians was described as challenging (II). The findings show little recognition by either nurses or physicians of the burden carried by the other. The nurses acknowledged that decisions were difficult, but they did not appear to recognize the moral implications for physicians. Similarly, the physicians did not pay any attention to the fact that nurses had to act upon decisions they might not agree with and find inappropriate for the patient (I, II).

Contextual barriers for lack of interdisciplinary cooperation

According to a Norwegian report (157), there is increasing fragmentation in the specialist health care services that creates problems for cooperation within the specialist health care services and between primary and specialist health services, and this can prevent offering good health care for patients with

chronic diseases, like COPD. The health care system, which is designed for the treatment of acute conditions and treat symptoms when they come, do not seem to handle the multiple needs of a patients with late-stage COPD.

International guidelines, Norwegian health care policy guidelines and healthcare legislation have stated that professionally responsible care and treatment are dependent on mutual processes (6 , 7 , 11 , 54). Findings in Papers I and II show that nurses and physicians often have different opinions regarding whose values should carry the most moral weight, but those value discussions were never brought to the table to share valuable views regarding the patient's situation. Physicians rarely knew what the nurses actually thought (I). The nurses, perceived themselves in a subordinate position which hindered them in communication with the physicians (II). I argue that this lack of interdisciplinary collaboration is partly related to a hierarchical hospital culture, lack of guidelines and clear leadership, which were also found in other studies (74 , 158 , 159).

In order to impose structure on communication and information, guidelines could be helpful. Guidelines alone will not ensure that communication improves, but they may help safeguard the processes leading to a decision. Studies have shown that guidelines might give specific advice for how to talk about difficult and sensitive issues and how to avoid or resolve conflicts (74 , 160). An international research and innovation program called MACIC (<http://magicproject.org/share-it>) is developing new professional guidelines and tools that healthcare personnel and patients can use jointly to share knowledge about advantages and disadvantages of treatment (161).

Our findings show, however, that professionals need to develop better skills in communication about EOL (I, II). Communication skills can be learned through collaboration in interdisciplinary teams discussing cases that are ethically and medically challenging regarding end- of- life care. Skills can be learned in practical workshops (162). It is also possible to learn and practice the ability to listening with sensitivity and being attentive (163). The University of Leuven in Belgium has an ethical simulation lab, where physicians and nurses can practice and improve skills in, e.g. ethical decision-making. A feature that may prove useful is the preparation of Internet-based decision-making tools that the healthcare personnel and patient can use jointly or the patient can study at home with his or her relatives (164).

I argue that leadership plays a central role in ensuring interdisciplinary collaboration in decision-making processes. To avoid placing the responsibility for collaboration on individual clinicians, there is a need for structured and planned meetings initiated by leaders. These meetings could provide a place for all team members to discuss motivations for their proposed plans for the patients, including conversation, appropriate use of MV or NIV treatment and preferred care.

The nurses' proximity to their patients

Nurses are the ones who are continuously present at the bedside and more intimately involved with patients and their family. The physical closeness inherent in the nurse-patient relationship has been central definitive feature of the discipline of nursing and its moral ideals and has provided nurses with a sense of identity (149). Relational proximity encourages moral agents to act, and therefore has an impact on moral responsiveness, namely the capacity to be sensitive to moral concerns and to seek solutions (165). Nortvedt claims that proximity to the patient's vulnerabilities, in many cases, intuitively creates a strong sense of duty to attend to the particular needs of a patient (166). The findings in Paper II show that this relational proximity facilitates nurses' awareness of clinical cues, and their sensitivity to bodily discomfort and the patients' subjective experiences of their illness. The professional values presented in ethical guidelines describe nursing care as being rooted in the inherent dignity of individuals, and respect for patient dignity is a fundamental value in nursing care (149). According to the nurses, patients with late-stage COPD, had experienced several losses that influenced on their sense of dignity: loss of control because of breathlessness, loss of autonomy and heightened physical dependency with being helpless and confined to bed and receiving treatment with MV or NIV at the end of their lives.

Witnessing suffering and undignified care was perceived by the nurses as a core problem in caring for the patients with severe COPD: *'We observe all needles, the pressure sores due to the ventilation mask, and the patient's anxiety. This futile treatment is a kind of medical rape and it is undignified'*.

The nurses described experiences of loneliness and resignation. Even though the nurses grew to know the patients well and they were aware of their suffering and undignified care, they failed to act upon this knowledge. Professional empathy, though, does not only require that one identify and understand the patient's experiences, one should also respond to the patient's feelings and needs (155). I will argue that hardly ever acting upon patients' needs and feelings is not in the patient's best interests and it is a repudiation of liability. Nurses' inability to act upon the patients' need is a paradox when it comes to

proximity. As shown above, proximity may propel nurses to act, but it can also propel them to ignore or abandon the patients' vulnerable situations. For this reason, proximity can be perilous and lead to moral ambiguity and moral distress (165). Moral distress develops in situations where healthcare providers cannot fulfill their moral obligations to patients or fail to pursue what they believe to be the correct course of action due to forces often out of their control (167). Research in several studies has reported that, compared with physicians, nurses experience more moral distress when confronted with situations where they cannot fulfill their moral obligations (168 , 169 , 170). Storaker (171) found that lack of time for ethical reflection leads to increased moral distress and 'emotional immunization' which involves moral blindness as well as being resistant to impressions. The findings in Paper II showed that 'emotional immunization' might be a result of actions against caring values rather than a lack of time for reflection. This emotional blindness may be one reason for lack of responsibilities to advocate what is at stake for the patients. Heggstad, (151) show in her study that nursing students sometimes experienced being overwhelmed by emotions, making it difficult to maintain a professional distance. Nortvedt describes this as 'immature empathy' where one does not manage to distinguish between one's own feelings and those of others (95). It is reasonable to conclude that this overwhelming emotion may increase the nurses' experiences of moral distress. For the nurses in the study, feelings of moral distress were related to moral challenges, regarding the most basic moral values of life and death, right and wrong. It also included considerations whether or not to participate in treatment that was not in the patient's best interests, and providing what was perceived to be futile and undignified care for their patients.

Patients' experiences of being seriously ill

Paper III, focus on the patients' experiences of being seriously ill and how they perceived their role in participating in decision-making regarding treatment and care. I will argue that the patients' poor physical and emotional condition, lack of trust, and feelings of shame due self-inflicted disease hindered them to initiate their legal right to be involved in decision-making processes.

Several of the patients talked about their grief, loneliness, anxiety and lack of confidence that their needs would be met (III). The patients used expressions like 'afraid of being suffocated', 'feeling small and alone', to describe their physical, existential and emotional challenges. Moreover, they described their experiences of not being informed and included in decision- making processes regarding MV and NIV as having nobody to talk to, not being considered as important, being ignored, and feeling guilty

for having a self-inflicted disease. However, these experiences were intertwined with patient's perceptions of their options to participate in decision-making processes.

Breathlessness, loneliness and anxiety

Findings in Paper III showed that patients experienced their breathlessness as life threatening and frightening. Additionally, they described feelings of loneliness and emotional distress. Patients described the sensation of breathlessness as having a body that was vulnerable, not trustworthy and dependent on others. They experienced that anxiety and breathlessness were intertwined and led to a vicious cycle wherein they felt they were losing control. One patient said it clearly: *'having hunger for air gives me a feeling of panic and not being able to breath without help makes me feel very fragile'*.

The impact of breathlessness pervaded patients' daily life, but their main worry was the unpredictable episodes of exacerbation. Breathing is a complex phenomenon that is not fully understood and involves emotions, bodily sensation and thoughts (172). Breathlessness is a debilitating symptom that affects quality of life, exercise tolerance and mortality in various disease conditions. Lansing (173) shows in a review article that there is a growing body of evidence that there is an affective and emotional dimension to dyspnea that does not entirely depend on its sensory strength. Additionally, the findings in Paper III show patients experienced an existential dimension of breathlessness related to their feelings of being at the threshold of life and death during periods of exacerbation. They were alive, but at the same time needed help to stay alive. This strong bodily experience of breathlessness and the sensation of being at a kind of tipping point has been shown in other studies (174 , 175).

The patients described this existential dimension as a strong feeling of being alone. Some of the patients reported not having anyone to talk to about their worries and grief regarding their severe illnesses. The symptoms of breathlessness limit the ability of patients with COPD to sustain physical and social activities. Eight of ten participating patients used fixed oxygen therapy, which made them more homebound. Adhering to oxygen therapy was described as complex and difficult, including physical difficulty of using oxygen and a sense of social stigma, which made them even more socially isolated. Their symptom burden made the patients gradually more dependent on others, but at the same time, they experienced stronger feelings of loneliness. None of the patients were receiving opioids. Opioids are recommended by multiple evidence-based guidelines for the relief of dyspnea (176 , 177 , 178).

Patients were constantly on alert for unpredictable exacerbations. Many of the participants were afraid of being suffocated due to the worsening of their disease. Even though some of the patients tried to ask healthcare personnel about what would happen, they did not understand the information they were given or the words used to explain the illness trajectory in the case of exacerbation of the disease. As one of the participating patient said: *‘I have tried to ask the physicians about the change for relief from being suffocated, but he said that I will be unconscious before I die. I do not know how long I have to struggle before I go unconscious’*.

None of the patients said that they felt confident that they would have relief from pain and breathlessness at the end of their lives. They were not introduced to planned care, which could make them feel sure of being comfortable, and cared for when their conditions worsens. Instead, most of them had nobody to talk to and nobody to lean on in a very vulnerable situation (III). This led to a lack of confidence that healthcare personnel would act in their best interests.

Lack of trust

Studies show that patients with critical illnesses could benefit from a strong relationship with healthcare personnel, where trust is a central factor. Moreover, it seems that trust can predict for patients’ desire to participate in decision-making about their medical treatment and care (179 , 180 , 181). Most of the patients in sub-study III, have been suffering from COPD for many years (mean =11 years), during which time they have been in and out of hospitals several times (mean =5 times previous year). However, findings in Paper III reveal that patients experienced that neither nurses nor physicians invited them to participate in dialogue where openness, consolation, and the promotion of hope regarding illness relief were themes.

Trust is multifaceted in the medical context. It encompasses a patient’s belief in experts’ medical knowledge and ability to carry out implemented plans of care. It also encompasses a belief that the physicians and the nurses are in fact their advocates and that the healthcare professionals highly value the patient wishes and look out for their best interests (181 , 182 , 183). Fugelli writes in Gawande’s book that the good relation between physician and patient is based on trust and consists of three core elements: to want the best, to share power and to be honest (184). In acute and critical situations, patients are at the mercy of staff and fully dependent on their willingness to help them with breathing support. This makes them vulnerable. In this situation patient is not capable to participate in making a

decision, and invitation to participate may rise to confusion or a sense of insecurity. However, the patients in our study, experienced asymmetry in power and no willingness from the health care personnel to share this power (III). The patients did not believe that healthcare personnel were their advocates because they experienced not being listened to, not being understood or taken seriously as competent people capable of being involved in decision-making regarding their own treatment and care. Patients received treatment like NIV and MV without being asked whether this was what they wanted. Additionally, they did not know that they had the opportunity to be involved in decision-making processes. Nobody asked them what they hoped for instead, the physicians seemed to have a narrow understanding of patients' hopes as a hope to survive at any cost (I). Asking patients how much information they want seem to be a good approach to understanding individuals' needs (144). Findings show that patient hopes were to a great extent, related to relief of breathlessness and being able to die without being suffocated (III). As long as physicians define and control what information is relevant for their patients, and nurses are absent in decision-making processes, patient autonomy is subject to severe limitations, and is beyond their control. It is reasonable to draw the conclusion that patients' trust in clinicians is lacking or has been compromised.

Patients' feelings of shame due to self-inflicted disease

Many of the participating patients blamed themselves for bringing the disease into their lives. All of the participating patients in our study used to smoke before they got severely ill. Anti-tobacco movement's effort to stigmatize smoking has also stigmatized smokers (185). Their feelings of guilt and shame were related to their belief that they had done something (smoking) they should not have done (III). As one patient said: *'What hurts me the most is that people say that the illness is my own fault. I know that I should not have smoked, and that makes me feel ashamed'*. Some of the patients talked about avoiding going out in public because they felt extremely ashamed when they were coughing, struggling for breath and supplemental oxygen (III). The patients described this as signs of their disabilities. At the same time, witnessing these symptoms may make bystanders uncomfortable, leading to more social awkwardness. The patients felt stigmatized in society as well as in the health care system. One of the patients characterized this feeling as being 'second –class people'.

According to Goffman, people may feel stigmatized when those around feel that there is a difference between a person's expected social identity and his or her actual identity (186). People who experience a high degree of stigmatization often have low self-confidence and a low degree of control over their

daily life situation (186). This is in line with studies that highlight that the feeling of shame of patients with COPD influence their contacts with health care professionals in a negative way (187 , 188). Additionally, experiences of guilt and the shame of having a self-inflicted disease may delay the information-seeking process, reduce active engagement with interventions and contribute to poor self-management (189). Feeling stigmatized may affect individuals deeply, and reinforce their contribution to their social isolation and depression (190).

In Norway, the relationship between smoking habits and socio-economic status is well documented (191). A study by Album and Westin revealed a hierarchy of medical diagnoses, with thorax surgery on top and patients with chronic diseases (especially so-called self-inflicted diseases) with no chances of being healed on the bottom (192). Patients with late- stage COPD are low on the medical hierarchy. Despite legal regulations when it comes to justice as a core value in Norwegian prioritization policies (91), there is clear tendencies that health care personnel does priorities patients with chronical self-inflicted diseases lower than other patients (4 , 193 , 194). Although Norway is a highly egalitarian country with a free universal healthcare system, a recent study indicates that surgery and radical palliative radiotherapy were under-used among the elderly patients with lung cancer, who had a lower income and education (195). This finding may indicate that patients with high education or high income are better informed about their treatment options, and may be more active in decision- making processes with their physician. If so, this is contrary to justice as a principle in Norwegian health care policy. However, one could also speculate that healthcare personnel's lack of identification in patients with lower socioeconomic which may lead to a weaker understanding and engagement in these patients' situations. Thoughts like 'it could have been me', which is a prerequisite for empathy, seems perhaps to be too far away, both because of the character of the illness and the perceived distance between the patients and the healthcare personnel related to different socio-economic status. Studies show that shaming attributes may arise from interactions with healthcare professionals, who believe patients with COPD are to blame for their disease, resulting in patients feeling stigmatized (185 , 196).

The findings in Papers I, II, confirm patients' experiences are of low priority due to their diagnosis and their social and intellectual status. Healthcare personnel experienced that patients were unequal in intellectual and social status. One physician even said: *'these patients are not exactly academics- perhaps they can live in an ignorant bliss'*.

In my opinion, this attitude, where healthcare personnel consider themselves better or above their patients, is a possible reason for the lack of understanding and involvement towards the patients. Vetlesen (197) discusses the role of the physician in relation to patient. He argues that medical education does not sufficiently counter the widespread perception of physicians as being in some way 'above' other people, including their patients. In contrast the significance of vulnerability, understood as a deep-seated, non-optional feature of being human, should be a shared feeling between the physician and the patient. He argues that the vulnerability that physicians share with patients is a prerequisite in order to understand of the patient's situation when it comes to illnesses and concerns. However, I argue that the patients in our study did not seem to have a balanced relationship with either their nurses or their physicians.

7 Conclusion

In this thesis, the findings highlighted that patients with late-stage COPD experienced a fragile and burdensome life and a reduced quality of life. The patients told about shame, distrust and blame. They experienced being stigmatized from healthcare professionals and by themselves. Most of the patients wanted to be included in decision-making processes regarding MV and NIV. Nevertheless, they experienced that they were not considered as an important part in decisions about their own treatment and care. We found that physicians were the sovereign decision-makers, even though they felt that the decision-making process was challenging and lonely. In spite of these feelings, they rarely considered sharing the decision-making with the patients and nurses. This may indicate that the decision-making process is influenced by a paternalistic culture.

The nurses found themselves in a cure-oriented treatment culture wherein they were unable to stand up for their caring values. They experienced being caught in the middle between loyalty to the physicians and their commitments to their patients. The nurses failed to advocate for the patients and their own role in the decision-making processes.

Values such as dignity, indignity, uncertainty, were not made transparent or were rarely discussed when making decisions of NIV or MV. I will argue that it is of imperative that clinical and ethical challenges are discussed in an open atmosphere in the clinical setting and with patients and their relatives. Not doing so may have serious consequences for patients' experiences of welfare, autonomy and trust and it is a violation of health care laws and politics.

The findings from the thesis elucidated the need for improvements in end-of-life care for patients with late-stage COPD. The patients need to be included in decisions. Additionally, interdisciplinary cooperation between nurses and physicians has to be strengthened to ensure that the complex and complicated decisions are made based on knowledge, values and preferences from both perspectives.

One way to promote respect for the autonomy of patients with COPD, is ACP (38). I will argue that ACP should become an institutionalized part of the health care services for patients with COPD in late-stage. Patients should be encouraged to regularly discuss their values preferences and hopes regarding end-of-life-with care providers and these discussions should be documented for future treatment and

care. It is important to emphasize that healthcare professionals are likely to need support and encouragement to find appropriate opportunities to initiate these discussions.

8 Suggestions for further research

GOLD guidelines provide limited recommendations for the care of ‘end-stage’ COPD (11). This underlines the importance of further research that may improve our understanding of the needs of the patients with COPD and the care we provide for these patients.

To provide competent care for patients with late-stage COPD, it is essential to understand how these patients experience their illness. Several of the participating patients experienced a heavy symptom burden, especially related to breathlessness. There are few prospective studies of breathing discomfort and the significance nursing competency for minimizing suffering. In order to understand the complexity of breathlessness as a phenomenon, further research on patient-reported experiences is needed. Additionally, there is a growing awareness that dyspnea, like pain, is a multidimensional experience (198). A recent instrument, the Multidimensional Dyspnea Profile, assesses discomfort and modality of sensation and emotional response (172). This instrument has not been translated into Norwegian. A suggestion for further research would be to translate, validate and clinically test this instrument on patients with COPD. This validation could be a starting point for better implementation of measures to relieve the symptoms of breathlessness.

I will also emphasize the importance of further studies regarding how patients experience the treatment with NIV. Further exploratory qualitative studies are unlikely to add to this theme, but hearing the experiences of a larger number of patients may nuance our understanding of living with COPD, and the experiences of treatment with NIV.

The findings in this study are in line with findings from other studies that show that the information needs of patients with late-stage COPD are poorly understood (55 , 144). Many of the patients are unaware that their conditions is terminal (III). Training programs for healthcare personnel are necessary to address the lack of understanding of the patients’ need for better palliative care and involvement in decision-making processes. There is also a need for change in healthcare professional culture to promote greater respect for patient autonomy. Achieving this change requires more research to determine optimal methods for involving patients in decisions. This is in line with a recent report from the Norwegian Knowledge Centre for the Health Services, that states that there is a need for research about what happens during the decision-making process and what factors are important and necessary to make the best possible decisions (81).

Future studies should focus on developing guidelines for communication strategies. There is a need to develop a ‘communication-guide’ to facilitate difficult conversations between healthcare personnel and the patients about NIV or MV when the patient’s condition is stable.

Additionally, studies should focus on how recommended advanced care planning for older patients with late-stage COPD can be successfully implemented in clinical practice to prevent both over-and under treatment by using MV and NIV.

Future studies should focus on how the specialist health care services and the primary health services can improve their cooperation in the best interest of patients with chronic diseases like COPD. In order to meet the multiple care of patients with late-stage COPD in a better way, further studies should focus on how to coordinate care for these patients.

9. REFERENCES

1. Halvorsen, Førde, Nortvedt. Professional challenges of bedside rationing in intensive care. *Nurs Ethics*. 2008;15(6):715-728.
2. Rostami S, Jafari H. nurses' perceptions of futile medical care. *Mater Sociomed*. 2016;28(2):151-155.
3. Willmott L, White B, Gallois C, Parker M, Graves N, Winch S, et al. Reasons doctors provide futile treatment at the end of life: a qualitative study. *J Med Ethics*. 2016;42(8):496-503.
4. Halvorsen K, Førde R, Nortvedt P. The principle of justice in patient priorities in the intensive care unit: the role of significant others. *J Med Ethics*. 2009;35(8):483-487.
5. Lov om pasient- og brukerrettigheter. (Pasient- og brukerrettighetsloven) [The patient's and user's rights act] 1999. Available from: <https://lovdata.no/dokument/NL/lov/1999-07-02-63>.
6. Norwegian Directorate of Health. Kols: Nasjonal faglig retningslinje og veileder for forebygging, diagnostisering og oppfølging (Nasjonale faglige retningslinjer IS-2029) [COPD: National professional guidelines and guide for prevention, diagnosis and monitoring]. Oslo, Norway: Author, 2012.
7. Norwegian Directorate of Health. Livsforlengende behandling: Beslutningsprosesser ved begrensning av livsforlengende behandling (Veileder IS-2091) [Decision-making processes in limitation of life-prolonging treatment]. Oslo, Norway: Author, 2013.
8. Spathis A, Booth S. End of life care in chronic obstructive pulmonary disease: in search of a good death. *Int J Chron Obstruct Pulmon Dis*. 2008;3(1):11-29.
9. Philip J, Gold M, Brand C, Douglass J, Miller B, Sundararajan V. Negotiating hope with chronic obstructive pulmonary disease patients: a qualitative study of patients and healthcare professionals. *Intern Med J*. 2012;42(7):816-822.
10. Beauchamp, Childress. *Principles of Biomedical Ethics*. 7th ed. Beauchamp TL, Childress J, editors. New York: Oxford University Press 2013.
11. Global Initiative for Chronic Obstructive Lung Disease (GOLD). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease 2015. Available from: http://www.goldcopd.it/materiale/2015/GOLD_Report_2015.pdf.
12. Buist AS, McBurnie MA, Vollmer WM, Gillespie S, Burney P, Mannino DM, et al. International variation in the prevalence of COPD (the BOLD Study): a population-based prevalence study. *Lancet*. 2007;370(9589):741-750.
13. Halvorsen T, Martinussen PE. The geography of chronic obstructive pulmonary disease: a population-based study of Norway. *Soc Sci Med*. 2014;111:25-34.
14. Waatevik M, Skorge TD, Omenaas E, Bakke PS, Gulsvik A, Johannessen A. Increased prevalence of chronic obstructive pulmonary disease in a general population. *Respir Med*. 2013;107(7):1037-1045.

15. Soriano JB, Visick GT, Muellerova H, Payvandi N, Hansell AL. Patterns of comorbidities in newly diagnosed COPD and asthma in primary care. *Chest*. 2005;128(4):2099-2107.
16. Lange P, Moll L. Komorbiditet ved KOL. In: Moll L, Lange P, Dahl B, editors. *KOL sykdom, behandling og organisasjon*. Copenhagen, Denmark: Munksgaard 2011. p. 157-165.
17. Rodriguez-Roisin R. Toward a consensus definition for COPD exacerbations. *Chest*. 2000;117(5 Suppl 2):398s-401s.
18. Disler RT, Green A, Luckett T, Newton PJ, Inglis S, Currow DC, et al. Experience of advanced chronic obstructive pulmonary disease: metasynthesis of qualitative research. *J Pain Symptom Manage*. 2014;48(6):1182-1199.
19. Lilly EJ, Senderovich H. Palliative care in chronic obstructive pulmonary disease. *J Crit Care*. 2016;35:150-154.
20. Bourke S, Peel E. Palliative care of chronic progressive lung disease. *Clin Med*. 2014;14(3):325.
21. Boland J, Martin J, Wells AU, Ross JR. Palliative care for people with non-malignant lung disease: summary of current evidence and future direction. *Palliat Med*. 2013;27(9):811-816.
22. Yohannes AM. Palliative care provision for patients with chronic obstructive pulmonary disease. *Health Qual Life Outcomes*. 2007;5:17.
23. Varkey B. Opioids for palliation of refractory dyspnea in chronic obstructive pulmonary disease patients. *Curr Opin Pulm Med*. 2010;16(2):150-154.
24. Mas A, Masip J. Noninvasive ventilation in acute respiratory failure. *Int J Chron Obstruct Pulmon Dis*. 2014;9:837-852.
25. Torheim H, Gjengedal E. How to cope with the mask? Experiences of mask treatment in patients with acute chronic obstructive pulmonary disease-exacerbations. *Scand J Caring Sci*. 2010;24(3):499-506.
26. Chandra D, Stamm JA, Taylor B, Ramos RM, Satterwhite L, Krishnan JA, et al. Outcomes of noninvasive ventilation for acute exacerbations of chronic obstructive pulmonary disease in the United States, 1998-2008. *Am J Respir Crit Care Med*. 2012;185(2):152-159.
27. Lightowler JV, Wedzicha JA, Elliott MW, Ram FS. Non-invasive positive pressure ventilation to treat respiratory failure resulting from exacerbations of chronic obstructive pulmonary disease: Cochrane systematic review and meta-analysis. *BMJ*. 2003;326(7382):185.
28. Keenan SP, Mehta S. Noninvasive ventilation for patients presenting with acute respiratory failure: the randomized controlled trials. *Respir Care*. 2009;54(1):116-126.
29. Nava S, Navalesi P, Conti G. Time of non-invasive ventilation. *Intensive Care Med*. 2006;32(3):361-370.
30. Roberts CM, Lopez-Campos JL, Pozo-Rodriguez F, Hartl S. European hospital adherence to GOLD recommendations for chronic obstructive pulmonary disease (COPD) exacerbation admissions. *Thorax*. 2013;68(12):1169-1171.

31. Struik FM, Lacasse Y, Goldstein R, Kerstjens HM, Wijkstra PJ. Nocturnal non-invasive positive pressure ventilation for stable chronic obstructive pulmonary disease. *Cochrane Database Syst Rev.* 2013;6:Cd002878.
32. Struik FM, Sprooten RT, Kerstjens HA, Bladder G, Zijnen M, Asin J, et al. Nocturnal non-invasive ventilation in COPD patients with prolonged hypercapnia after ventilatory support for acute respiratory failure: a randomised, controlled, parallel-group study. *Thorax.* 2014;69(9):826-834.
33. Carlucci A, Guerrieri A, Nava S. Palliative care in COPD patients: is it only an end-of-life issue? *Eur Respir Rev.* 2012;21(126):347-354.
34. Smith TA, Davidson PM, Lam LT, Jenkins CR, Ingham JM. The use of non-invasive ventilation for the relief of dyspnoea in exacerbations of chronic obstructive pulmonary disease; a systematic review. *Respirology.* 2012;17(2):300-307.
35. Miller D, Fraser K, Murray I, Thain G, Currie GP. Predicting survival following non-invasive ventilation for hypercapnic exacerbations of chronic obstructive pulmonary disease. *Int J Clin Pract.* 2012;66(5):434-437.
36. Lopez-Campos JL, Jara-Palomares L, Munoz X, Bustamante V, Barreiro E. Lights and shadows of non-invasive mechanical ventilation for chronic obstructive pulmonary disease (COPD) exacerbations. *Ann Thorac Med.* 2015;10(2):87-93.
37. Patel K, Janssen DJ, Curtis JR. Advance care planning in COPD. *Respirology.* 2012;17(1):72-78.
38. MacPherson A, Walshe C, O'Donnell V, Vyas A. The views of patients with severe chronic obstructive pulmonary disease on advance care planning: a qualitative study. *Palliat Med.* 2013;27(3):265-272.
39. Janssen DJ, Wouters EF, Spruit MA. Psychosocial consequences of living with breathlessness due to advanced disease. *Curr Opin Support Palliat Care.* 2015;9(3):232-237.
40. Pinnock H, Kendall M, Murray SA, Worth A, Levack P, Porter M, et al. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ.* 2011;342:d142.
41. Borge CR, Wahl AK, Moum T. Pain and quality of life with chronic obstructive pulmonary disease. *Heart Lung.* 2011;40(3):e90-101.
42. de Torres JP, Casanova C, Marin JM, Pinto-Plata V, Divo M, Zulueta JJ, et al. Prognostic evaluation of COPD patients: GOLD 2011 versus BODE and the COPD comorbidity index COTE. *Thorax.* 2014;69(9):799-804.
43. Currow DC, Smith J, Davidson PM, Newton PJ, Agar MR, Abernethy AP. Do the trajectories of dyspnea differ in prevalence and intensity by diagnosis at the end of life? A consecutive cohort study. *J Pain Symptom Manage.* 2010;39(4):680-690.
44. Blinderman CD, Homel P, Billings JA, Tennstedt S, Portenoy RK. Symptom distress and quality of life in patients with advanced chronic obstructive pulmonary disease. *J Pain Symptom Manage.* 2009;38(1):115-123.
45. Johnson MJ, Bowden JA, Abernethy AP, Currow DC. To what causes do people attribute their chronic breathlessness? A population survey. *J Palliat Med.* 2012;15(7):744-750.

46. Kessler R, Stahl E, Vogelmeier C, Haughney J, Trudeau E, Lofdahl CG, et al. Patient understanding, detection, and experience of COPD exacerbations: an observational, interview-based study. *Chest*. 2006;130(1):133-142.
47. Bereza BG, Troelsgaard Nielsen A, Valgardsson S, Hemels ME, Einarson TR. Patient preferences in severe COPD and asthma: a comprehensive literature review. *Int J Chron Obstruct Pulmon Dis*. 2015;10:739-744.
48. Bailey PH. Death stories: acute exacerbations of chronic obstructive pulmonary disease. *Qual Health Res*. 2001;11(3):322-338.
49. Kvangarsnes M, Torheim H, Hole T, Ohlund LS. Narratives of breathlessness in chronic obstructive pulmonary disease. *J Clin Nurs*. 2013;22(21-22):3062-3070.
50. Janssen DJ, Wouters EF, Schols JM, Spruit MA. Care dependency independently predicts two-year survival in outpatients with advanced chronic organ failure. *J Am Med Dir Assoc*. 2013;14(3):194-198.
51. Buxton KL, Stone RA, Buckingham RJ, Pursey NA, Roberts CM. Current and planned palliative care service provision for chronic obstructive pulmonary disease patients in 239 UK hospital units: comparison with the gold standards framework. *Palliat Med*. 2010;24(5):480-485.
52. Lal AA, Case AA. Palliation of chronic obstructive pulmonary disease. *Ann Palliat Med*. 2014;3(4):276-285.
53. Azoulay E, Demoule A, Jaber S, Kouatchet A, Meert AP, Papazian L, et al. Palliative noninvasive ventilation in patients with acute respiratory failure. *Intensive Care Med*. 2011;37(8):1250-1257.
54. Syse A. *Pasientrettighetsloven: Med kommentarer* 3rd ed. Oslo: Gyldendal Akademisk; 2009.
55. Momen N, Hadfield P, Kuhn I, Smith E, Barclay S. Discussing an uncertain future: end-of-life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis. *Thorax*. 2012;67(9):777-780.
56. Stephen N, Skirton H, Woodward V, Prigmore S, Endacott R. End-of-life care discussions with nonmalignant respiratory disease patients: a systematic review. *J Palliat Med*. 2013;16(5):555-565.
57. Curtis JR, Engelberg RA, Nielsen EL, Au DH, Patrick DL. Patient-physician communication about end-of-life care for patients with severe COPD. *Eur Respir J*. 2004;24(2):200-205.
58. Izumi S, Nagae H, Sakurai C, Imamura E. Defining end-of-life care from perspectives of nursing ethics. *Nurs Ethics*. 2012;19(5):608-618.
59. Au DH, Udris EM, Fihn SD, McDonnell MB, Curtis JR. Differences in health care utilization at the end of life among patients with chronic obstructive pulmonary disease and patients with lung cancer. *Arch Intern Med*. 2006;166(3):326-331.
60. Gaspar C, Alfarroba S, Telo L, Gomes C, Barbara C. End-of-life care in COPD: a survey carried out with Portuguese pulmonologists. *Rev Port Pneumol*. 2014;20(3):123-130.

61. Goodridge D, Duggleby W, Gjevre J, Rennie D. Caring for critically ill patients with advanced COPD at the end of life: a qualitative study. *Intensive Crit Care Nurs*. 2008;24(3):162-170.
62. Gardiner C, Gott M, Small N, Payne S, Seamark D, Barnes S, et al. Living with advanced chronic obstructive pulmonary disease: patients concerns regarding death and dying. *Palliat Med*. 2009;23(8):691-697.
63. Knauff E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest*. 2005;127(6):2188-2196.
64. Carlucci A, Vitacca M, Malovini A, Pierucci P, Guerrieri A, Barbano L, et al. End-of-Life Discussion, Patient Understanding and Determinants of Preferences in Very Severe COPD Patients: A Multicentric Study. *Copd*. 2016:1-7.
65. Elkington H, White P, Higgs R, Pettinari CJ. GPs' views of discussions of prognosis in severe COPD. *Fam Pract*. 2001;18(4):440-444.
66. Gaber KA, Barnett M, Planchant Y, McGavin CR. Attitudes of 100 patients with chronic obstructive pulmonary disease to artificial ventilation and cardiopulmonary resuscitation. *Palliat Med*. 2004;18(7):626-629.
67. Lloyd-Williams M, Kennedy V, Sixsmith A, Sixsmith J. The end of life: a qualitative study of the perceptions of people over the age of 80 on issues surrounding death and dying. *J Pain Symptom Manage*. 2007;34(1):60-66.
68. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns*. 2014;94(3):291-309.
69. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665-1673.
70. Førde R, Aasland OG. Are end-of-life practices in Norway in line with ethics and law? *Acta Anaesthesiol Scand*. 2014;58(9):1146-1150.
71. Curtis JR. Palliative and end-of-life care for patients with severe COPD. *Eur Respir J*. 2008;32(3):796-803.
72. Murray SA, Boyd K, Sheikh A. Palliative care in chronic illness: We need to move from prognostic paralysis to active total care. *BMJ : British Medical Journal*. 2005;330(7492):611-612.
73. Hov R, Hedelin B, Athlin E. Being an intensive care nurse related to questions of withholding or withdrawing curative treatment. *J Clin Nurs*. 2007;16(1):203-211.
74. Lind R, Lorem GF, Nortvedt P, Hevroy O. Intensive care nurses' involvement in the end-of-life process--perspectives of relatives. *Nurs Ethics*. 2012;19(5):666-676.
75. Houben CH, Spruit MA, Wouters EF, Janssen DJ. A randomised controlled trial on the efficacy of advance care planning on the quality of end-of-life care and communication in patients with COPD: the research protocol. *BMJ Open*. 2014;4(1):e004465.

76. Hancock K, Clayton JM, Parker SM, Wal der S, Butow PN, Carrick S, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med.* 2007;21(6):507-517.
77. Bach V, Ploeg J, Black M. Nursing Roles in End-of-Life Decision Making in Critical Care Settings. *West J Nurs Res.* 2009;31(4):496-512.
78. Jensen HI, Ammentorp J, Erlandsen M, Ording H. Withholding or withdrawing therapy in intensive care units: an analysis of collaboration among healthcare professionals. *Intensive Care Med.* 2011;37(10):1696-1705.
79. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ.* 2010;340:c1345.
80. Benbenishty J, Ganz FD, Lippert A, Bulow HH, Wennberg E, Henderson B, et al. Nurse involvement in end-of-life decision making: the ETHICUS Study. *Intensive Care Med.* 2006;32(1):129-132.
81. Skår Å, Juvet L, Smedslund G, Bahus MK, Pedersen R, Fure B. Livets slutfase - om å finne passende behandlingsnivå og behandlingsintensitet for alvorlig syke og døende (Rapport fra Kunnskapssenteret nr. 18 – 2014) [End-of-life care - how to find the appropriate level and intensity of medical treatment of seriously ill and dying patients]. Oslo: Kunnskapssenteret; 2014.
82. Ruyter KW, Førde R, Solbakk JH. *Medisinsk og helsefaglig etikk* 2nd ed. Oslo: Gyldendal akademisk; 2007.
83. Jonsen A, Siegler M, Winslade W. *Clinical Ethics : A Practical Approach to Ethical Decisions in Clinical Medicine*, . 8th. ed. New York: McGrwa Hill; 2015.
84. Rachels J. Ethical theory and bioethics. In: Kuhse H, Singer PA, editors. *A Companion to Bioethics*. 2nd ed. West Sussex: Blackwell Publishing 2009. p. 15-24.
85. Ruyter KW, Solbakk JH, Førde R. *Medisinsk etikk: En problembasert tilnærming* Oslo: Gyldendal akademisk; 2000.
86. Gillon R. Defending the four principles approach as a good basis for good medical practice and therefore for good medical ethics. *J Med Ethics.* 2015;41(1):111-116.
87. Kristvik E. For whom and for what? Exploring the question of 'informed consent in treatment decision making processes. *Medische Antropologie* 2011;23:29-43.
88. Will JF. A brief historical and theoretical perspective on patient autonomy and medical decision making: Part I: The beneficence model. *Chest.* 2011;139(3):669-673.
89. Tranøy KE. *Medisinsk etikk i vår tid* 4th ed. Bergen: Fagbokforl.; 2005.
90. NOU 2014:12. *Åpent og rettferdig - prioriteringer i helsetjenesten*. Oslo: Helse- og omsorgsdepartementet; 2014.
91. NOU 1997:18. *Prioritering på ny: Gjennomgang av retningslinjer for prioriteringer innen norsk helsetjeneste*. Oslo: Sosial- og helsedepartementet; 1997.

92. Helsepersonelloven [Health Care Personnel Act]. Lov om helsepersonell m.v. 1999. Available from: <https://lovdata.no/lov/1999-07-02-64>.
93. Strech D, Synofzik M, Marckmann G. How physicians allocate scarce resources at the bedside: a systematic review of qualitative studies. *J Med Philos*. 2008;33(1):80-99.
94. Nortvedt P, Nordhaug M. The principle and problem of proximity in ethics. *J Med Ethics*. 2008;34(3):156-161.
95. Nortvedt P. Omtanke: En innføring i sykepleiens etikk Oslo: Gyldendal akademisk; 2012.
96. Pedersen., Hofmann B, Mangset M. Pasientautonomi og informert samtykke i klinisk arbeid [Patient autonomy and informed consent in clinical practice]. *Tidsskr Nor Lægeforen*. 2007;127(12):1644-1647.
97. Elliott C. Patients doubtfully capable or incapable of consent. In: Kuhse H, Singer PA, editors. *A Companion to Bioethics*. 2nd ed: Blackwell Publishing; 2012. p. 541-551.
98. Raymont V, Bingley W, Buchanan A, David AS, Hayward P, Wessely S, et al. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. *Lancet*. 2004;364(9443):1421-1427.
99. Befring AK, Ohnstad B. Helsepersonelloven: Med kommentarer 3rd ed. Bergen: Fagbokforlaget; 2010.
100. Sommer I, Pedersen R, Hoie AG, Nortvedt P. Retningslinjer for forhåndsvurdering av å avstå fra hjerte-lunge-redning [Guidelines on do-not-resuscitate orders in Norwegian hospitals]. *Tidsskr Nor Lægeforen*. 2007;127(10):1368-1369.
101. Nortvedt P, Pedersen R. Om døendes rettsstilling [Legal rights of the dying]. *Tidsskr Nor Lægeforen*. 2006;126(8):1080.
102. Bahun MK, Steen PA, Forde R. Law, ethics and clinical judgment in end-of-life decisions--how do Norwegian doctors think? *Resuscitation*. 2012;83(11):1369-1373.
103. Emanuel EJ, Emanuel LL. Proxy decision making for incompetent patients. An ethical and empirical analysis. *JAMA*. 1992;267(15):2067-2071.
104. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med*. 1997;44(5):681-692.
105. Houben CH, Spruit MA, Schols JM, Wouters EF, Janssen DJ. Patient-Clinician Communication About End-of-Life Care in Patients With Advanced Chronic Organ Failure During One Year. *J Pain Symptom Manage*. 2015;49(6):1109-1115.
106. Brinkmann S, Kvale S. *Interviews : learning the craft of qualitative research interviewing*. 3rd ed. Thousand Oaks, Calif: Sage; 2015.
107. Dahlberg K, Dahlberg H, Nyström M. *Reflective lifeworld research*. 2nd ed. Lund: Studentlitteratur; 2008.

108. Van Manen M. Researching lived experience: human science for an action sensitive pedagogy. London, Ont.: Althouse Press; 1997. XVIII, 202 s. p.
109. Webb C, Kevern J. Focus groups as a research method: a critique of some aspects of their use in nursing research. *J Adv Nurs*. 2001;33(6):798-805.
110. Svenaeus F. Fenomenologiska perspektiv på hälsa och sjukdom [Phenomenological perspectives of health and disease]. *Lakartidningen*. 2002;99(6):540-544.
111. Jacobsen B. Fænomenologi In: Tangaard L, Brinkmann S, editors. *Kvalitative metoder: En grundbog*. København: Hans Reizlerts forlag 2015. p. 217-240.
112. Gadamer H-G, Weinsheimer J, Marshall DG. *Truth and Method*. Revised second edition ed: United States: Bloomsbury UK; 2013.
113. Spence DG. Hermeneutic notions illuminate cross-cultural nursing experiences. *J Adv Nurs*. 2001;35(4):624-630.
114. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet*. 2001;358(9280):483-488.
115. Brinkmann S, Tanggaard L. *Kvalitative metoder : en grundbog*. 2. nd ed. Copenhagen, Denmark: Hans Reitzel; 2015.
116. Polit DF, Beck CT. *Resource manual for nursing research : generating and assessing evidence for nursing practice*. 9th ed. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins; 2012.
117. Malterud K. *Fokusgrupper som Forskningsmetode for Medisin og Helsefag* OSLO, Norway: Universitetsforlaget; 2012.
118. Tanggaard L, Brinkmann S. Kvalitet i kvalitative studier. In: Brinkmann S, Tanggaard L, editors. *Kvalitative metoder : en grundbog* 2.nd ed. København: Hans Reitzel; 2015.
119. Järvinen M, Mik-Meyer N. *Kvalitative metoder i et interaktionistisk perspektiv : interview, observationer og dokumenter*. Copenhagen, Denmark: Hans Reitzel; 2005.
120. Carpenter DR. Triangulation as a qualitative research strategy. In: Streubert HJ, Carpenter DR, editors. *Qualitative research in Nursing*. 5th ed. Philadelphia: Lippincott Williams & Wilkins; 2011. p. 349-359.
121. Krueger RA, Casey MA. *Focus groups : a practical guide for applied research*. 4th ed. Los Angeles, Calif: Sage; 2009.
122. Repstad P. *Mellom nærhet og distanse : kvalitative metoder i samfunnsfag* 4.th ed. Oslo, Norway: Universitetsforlaget; 2007.
123. Morgan D. *Focus Groups as Qualitative research* 2nd ed. Thousand Oaks, CA, USA: SAGE; 1997.
124. Lindseth A, Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci*. 2004;18(2):145-153.

125. Elwood SA, Martin DG. "Placing" Interviews: Location and Scales of Power in Qualitative Research. *The Professional Geographer*. 2000;52(4):649-657.
126. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res*. 2015.
127. Kitzinger J. Qualitative research. Introducing focus groups. *BMJ*. 1995;311(7000):299-302.
128. Debesay J, Naden D, Slettebo A. How do we close the hermeneutic circle? A Gadamerian approach to justification in interpretation in qualitative studies. *Nurs Inq*. 2008;15(1):57-66.
129. Malterud K. Systematic text condensation: a strategy for qualitative analysis. *Scand J Public Health*. 2012;40(8):795-805.
130. Fog J. Med samtalen som udgangspunkt: Det kvalitative forskningsinterview 2nd ed. Copenhagen, Denmark: Akademisk Forlag; 2004.
131. Braun V, Clarke V. Successful qualitative research : a practical guide for beginners. Los Angeles, Calif: Sage; 2013.
132. Creswell JW. Educational research : planning, conducting, and evaluating quantitative and qualitative research. 4th ed. ed. Boston, Mass: Pearson; 2012.
133. Morgan DL. Reconsidering the role of interaction in analyzing and reporting focus groups. *Qual Health Res*. 2010;20(5):718-722.
134. Hilden PK, Middelthon AL. Kvalitative metoder i medisinsk forskning – et etnografisk perspektiv [Qualitative methods in medical research--an ethnographic perspective]. *Tidsskr Nor Lægeforen*. 2002;122(25):2473-2476.
135. Gulbrandsen P. What's in shared decision-making for the physician? *Patient Educ Couns*. 2014;97(2):145-146.
136. Barnes S, Gardiner C, Gott M, Payne S, Chady B, Small N, et al. Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. *J Pain Symptom Manage*. 2012;44(6):866-879.
137. Fahim A, Kastelik JA. Palliative care understanding and end-of-life decisions in chronic obstructive pulmonary disease. *Clin Respir J*. 2014;8(3):312-320.
138. Borza LR, Gavrilovici C, Stockman R. Ethical models of physician--patient relationship revisited with regard to patient autonomy, values and patient education. *Rev Med Chir Soc Med Nat Iasi*. 2015;119(2):496-501.
139. Chu CM, Chan VL, Lin AW, Wong IW, Leung WS, Lai CK. Readmission rates and life threatening events in COPD survivors treated with non-invasive ventilation for acute hypercapnic respiratory failure. *Thorax*. 2004;59(12):1020-1025.

140. Titlestad IL, Lassen AT, Vestbo J. Long-term survival for COPD patients receiving noninvasive ventilation for acute respiratory failure. *Int J Chron Obstruct Pulmon Dis*. 2013;8:215-219.
141. Emanuel EJ, Fairclough DL, Wolfe P, Emanuel LL. Talking with terminally ill patients and their caregivers about death, dying, and bereavement: is it stressful? Is it helpful? *Arch Intern Med*. 2004;164(18):1999-2004.
142. Disler RT, Currow DC, Phillips JL, Smith T, Johnson MJ, Davidson PM. Interventions to support a palliative care approach in patients with chronic obstructive pulmonary disease: an integrative review. *Int J Nurs Stud*. 2012;49(11):1443-1458.
143. Cutcliffe JR, Herth KA. The concept of hope in nursing 5: hope and critical care nursing. *Br J Nurs*. 2002;11(18):1190-1195.
144. Curtis JR, Engelberg R, Young JP, Vig LK, Reinke LF, Wenrich MD, et al. An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer. *J Palliat Med*. 2008;11(4):610-620.
145. Hagerty RG, Butow PN, Ellis PM, Lobb EA, Pendlebury SC, Leighl N, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol*. 2005;23(6):1278-1288.
146. Reach G. Patient autonomy in chronic care: solving a paradox. *Patient Prefer Adherence*. 2013;8:15-24.
147. Disler RT, Green A, Lockett T, Newton PJ, Currow DC, Davidson PM. Experience of Advanced Chronic Obstructive Pulmonary Disease: Meta-synthesis of Qualitative Research. *J Pain Symptom Manage*. 2014.
148. Lind R, Nortvedt P, Lorem G, Hevroy O. Family involvement in the end-of-life decisions of competent intensive care patients. *Nurs Ethics*. 2013;20(1):61-71.
149. International Council of Nurses. The ICN codes of ethics for nurses 2012. Available from: http://www.icn.ch/images/stories/documents/about/icncode_english.pdf.
150. Pedersen R. Empathy development in medical education--a critical review. *Med Teach*. 2010;32(7):593-600.
151. Heggstad AK, Nortvedt P, Christiansen B, Konow-Lund AS. Undergraduate nursing students' ability to empathize: A qualitative study. *Nurs Ethics*. 2016.
152. Sprung CL, Woodcock T, Sjøkvist P, Ricou B, Bulow HH, Lippert A, et al. Reasons, considerations, difficulties and documentation of end-of-life decisions in European intensive care units: the ETHICUS Study. *Intensive Care Med*. 2008;34(2):271-277.
153. Halvorsen K, Forde R, Nortvedt P. Value choices and considerations when limiting intensive care treatment: a qualitative study. *Acta Anaesthesiol Scand*. 2009;53(1):10-17.
154. Pedersen R. Empathy: a wolf in sheep's clothing? *Med Health Care Philos*. 2008;11(3):325-335.
155. Nortvedt P. Omtanke: En innføring i sykepleiens etikk 2nd ed. Oslo: Gyldendal Akademisk 2016.

156. Eikeland HL, Ornes K, Finset A, Pedersen R. The physician's role and empathy - a qualitative study of third year medical students. *BMC Med Educ.* 2014;14:165.
157. The Norwegian Knowledge Centre for the Health Services, Oxman AD, Bjørndal A, Flottorp SA, Lewin S, Lindahl AK. Integrated health care for people with chronic conditions: A policy brief. Oslo, Norway: The Norwegian Knowledge Centre for the Health Services, 2008.
158. Lyngso AM, Godtfredsen NS, Frolich A. Interorganisational Integration: Healthcare Professionals' Perspectives on Barriers and Facilitators within the Danish Healthcare System. *Int J Integr Care.* 2016;16(1):4.
159. Ling T, Brereton L, Conklin A, Newbould J, Roland M. Barriers and facilitators to integrating care: experiences from the English Integrated Care Pilots. *Int J Integr Care.* 2012;12:e129.
160. Schaefer KG, Block SD. Physician communication with families in the ICU: evidence-based strategies for improvement. *Curr Opin Crit Care.* 2009;15(6):569-577.
161. Vandvik PO, Brandt L, Alonso-Coello P, Treweek S, Akl EA, Kristiansen A, et al. Creating clinical practice guidelines we can trust, use, and share: a new era is imminent. *Chest.* 2013;144(2):381-389.
162. Back AL, Arnold RM, Baile WF, Fryer-Edwards KA, Alexander SC, Barley GE, et al. Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med.* 2007;167(5):453-460.
163. Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. *Qual Saf Health Care.* 2006;15(4):264-271.
164. Legare F, Ratte S, Stacey D, Kryworuchko J, Gravel K, Graham ID, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev.* 2010(5):Cd006732.
165. Peter E, Liaschenko J. Perils of proximity: a spatiotemporal analysis of moral distress and moral ambiguity. *Nurs Inq.* 2004;11(4):218-225.
166. Nortvedt P. Needs, closeness and responsibilities. An inquiry into some rival moral considerations in nursing care. *Nurs Philos.* 2001;2:112-121.
167. Schwenzer KJ, Wang L. Assessing moral distress in respiratory care practitioners. *Crit Care Med.* 2006;34(12):2967-2973.
168. Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *J Adv Nurs.* 2001;33(6):707-715.
169. Piers RD, Azoulay E, Ricou B, DeKeyser Ganz F, Max A, Michalsen A, et al. Inappropriate care in European ICUs: confronting views from nurses and junior and senior physicians. *Chest.* 2014;146(2):267-275.
170. Hamric AB. Moral distress and nurse-physician relationships. *Virtual Mentor.* 2010;12(1):6-11.

171. Storaker A, Naden D, Saeteren B. From painful busyness to emotional immunization: Nurses' experiences of ethical challenges. *Nurs Ethics*. 2016.
172. Banzett RB, Schwartzstein RM. Dyspnea: Don't Just Look, Ask! *Am J Respir Crit Care Med*. 2015;192(12):1404-1406.
173. Lansing RW, Gracely RH, Banzett RB. The multiple dimensions of dyspnea: review and hypotheses. *Respir Physiol Neurobiol*. 2009;167(1):53-60.
174. Edwards S. Experiencing the Meaning of Breathing *The Indo-Pacific Journal of Phenomenology* 2006;6 (1).
175. Haugdahl HS, Storli SL, Meland B, Dybwik K, Romild U, Klepstad P. Underestimation of Patient Breathlessness by Nurses and Physicians during a Spontaneous Breathing Trial. *Am J Respir Crit Care Med*. 2015;192(12):1440-1448.
176. Marciniuk DD, Goodridge D, Hernandez P, Rucker G, Balter M, Bailey P, et al. Managing dyspnea in patients with advanced chronic obstructive pulmonary disease: a Canadian Thoracic Society clinical practice guideline. *Can Respir J*. 2011;18(2):69-78.
177. Qaseem A, Snow V, Shekelle P, Casey DE, Jr., Cross JT, Jr., Owens DK, et al. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: a clinical practice guideline from the American College of Physicians. *Ann Intern Med*. 2008;148(2):141-146.
178. Parshall MB, Schwartzstein RM, Adams L, Banzett RB, Manning HL, Bourbeau J, et al. An official American Thoracic Society statement: update on the mechanisms, assessment, and management of dyspnea. *Am J Respir Crit Care Med*. 2012;185(4):435-452.
179. Caress AL, Luker K, Woodcock A, Beaver K. A qualitative exploration of treatment decision-making role preference in adult asthma patients. *Health Expect*. 2002;5(3):223-235.
180. Brown RF, Butow PN, Henman M, Dunn SM, Boyle F, Tattersall MH. Responding to the active and passive patient: flexibility is the key. *Health Expect*. 2002;5(3):236-245.
181. Kraetschmer N, Sharpe N, Urowitz S, Deber RB. How does trust affect patient preferences for participation in decision-making? *Health Expect*. 2004;7(4):317-326.
182. Caplan AL. Odds and ends: trust and the debate over medical futility. *Ann Intern Med*. 1996;125(8):688-689.
183. Leland BD, Torke AM, Wocial LD, Helft PR. Futility Disputes: A Review of the Literature and Proposed Model for Dispute Navigation Through Trust Building. *J Intensive Care Med*. 2016.
184. Fugelli P. Forord. In: Gawande A, editor. *Å være dødelig: Om legekunst og livskvalitet [Being mortal: Medicine and what matters in the end]*. Oslo: Mime forlag; 2016.
185. Berger BE, Kapella MC, Larson JL. The experience of stigma in chronic obstructive pulmonary disease. *West J Nurs Res*. 2011;33(7):916-932.

186. Goffman E. Stigma : den avvikandes roll och identitet [Stigma notes on the management of spoiled identity]. 3rd ed. Stockholm, Sweden: Norstedt; 2011.
187. Odencrants S, Ehnfors M, Grobe SJ. Living with chronic obstructive pulmonary disease (COPD): part II. RNs' experience of nursing care for patients with COPD and impaired nutritional status. *Scand J Caring Sci*. 2007;21(1):56-63.
188. Lindgren S, Storli SL, Wiklund-Gustin L. Living in negotiation: patients' experiences of being in the diagnostic process of COPD. *Int J Chron Obstruct Pulmon Dis*. 2014;9:441-451.
189. Gysels M, Higginson IJ. The experience of breathlessness: the social course of chronic obstructive pulmonary disease. *J Pain Symptom Manage*. 2010;39(3):555-563.
190. Earnest MA. Explaining adherence to supplemental oxygen therapy: the patient's perspective. *J Gen Intern Med*. 2002;17(10):749-755.
191. Helsedirektoratet. Helsedirektoratets årlige rapport om arbeidet med å utjevne sosiale helseforskjeller: Folkehelsepolitisk rapport 2010 (IS-1856). Oslo, Norway: Author, 2010.
192. Album D, Westin S. Do diseases have a prestige hierarchy? A survey among physicians and medical students. *Soc Sci Med*. 2008;66(1):182-188.
193. Barr RG, Celli BR, Martinez FJ, Ries AL, Rennard SI, Reilly JJ, Jr., et al. Physician and patient perceptions in COPD: the COPD Resource Network Needs Assessment Survey. *Am J Med*. 2005;118(12):1415.
194. Pedersen W. En fremmed på benken : essays. Oslo: Universitetsforl.; 2010.
195. Nilssen Y, Strand TE, Fjellbirkeland L, Bartnes K, Brustugun OT, O'Connell DL, et al. Lung cancer treatment is influenced by income, education, age and place of residence in a country with universal health coverage. *Int J Cancer*. 2016;138(6):1350-1360.
196. Winstanley L. Risk assessment documentation in COC prescribing. *J Fam Plann Reprod Health Care*. 2008;34(2):137.
197. Vetlesen AJ. Profesjonell og personlig? Legerollen mellom vellykkethet og sårbarhet [Professional or private? Physician's role between success and vulnerability]. *Tidsskr Nor Laegeforen*. 2001;121(9):1118-1121.
198. Laviolette L, Laveneziana P. Dyspnoea: a multidimensional and multidisciplinary approach. *Eur Respir J*. 2014;43(6):1750-1762.

10. Appendices

Appendix 1:	Information to healthcare professionals and written informed consent
Appendix 2:	The interview guide focus group sub-study I, Physicians
Appendix 3:	The interview guide focus group sub-study II, Nurses
Appendix 4:	Information to patients and written informed consent
Appendix 5:	The interview guide sub-study III, Patients

Appendix 1: Information to healthcare professionals and written informed consent



UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

SKRIFTLIG INFORMERT SAMTYKKE

Forespørsel om deltakelse i forskningsprosjektet med tittelen:

Eldre med alvorlig KOLS: Omsorg, kliniske prioriteringer og respirasjonsstøttebehandling

Dette er en forespørsel til deg om du er villig til å delta i et forskningsprosjekt om KOLS og respirasjonsstøttebehandling. Studien er en del av stipendiat, sykepleier og høgskolelektor Heidi Jerpseth sitt doktorgradsarbeid ved senter for medisinsk etikk, universitetet i Oslo (UiO). Førsteamanuensis Kristin Halvorsen ved Høgskolen i Oslo og Akershus er prosjektleder og hovedveileder. Professor Per Nortvedt, senter for medisinsk etikk, UiO er medveileder. Prosjektet er finansiert av Ekstrastiftelsen, Landsforeningen for Hjerte og Lungesyke (LHL).

Bakgrunn og hensikt

KOLS er en av de raskest voksende sykdommer i verden og øker mest hos de som er over 60 år. I Norge er 7 % av befolkningen diagnostisert med KOLS, og man antar at det er flere som lever med en underdiagnostisert KOLS lidelse. Forskning og erfaring viser at pasienter med KOLS har nedsatt livskvalitet og opplever det belastende å leve med sin sykdom. Internasjonale studier, viser at 20-30 % av pasienter med KOLS, som behandles på intensivavdelinger, blir respiratorbehandlet. Helsetjenesten

trenger mer kunnskap om ulike sider ved det å leve med alvorlig KOLS for å gi pasientgruppen best mulig behandling.

- I. Hensikten med denne studien er å undersøke hvordan eldre pasienter med alvorlig KOLS har opplevd å bli respirasjonsstøttebehandlet. Likeledes vil studien belyse hvordan pasienten selv er delaktig i beslutningsprosessen omkring egen sykdom og behandling i forhold til respirasjonsstøttebehandling
- II. Undersøke hvordan leger og sykepleiere begrunner beslutninger om respirasjonsstøttebehandling av eldre pasienter med alvorlig KOLS (GOLD III-IV).

Hva innebærer studien?

Studien vil innebære for deg at du er villig til å la deg intervju om dine opplevelser og erfaringer omkring respirator /NIV-behandling for disse alvorlig syke KOLS pasientene. Intervjuene vil foregå ved at undertegnede og en annen forsker, vil ha et fokusgruppeintervju med sykepleiere og leger som er med i beslutningsprosessen om respirator/NIV-behandling for de alvorlig syke KOLS pasientene. Intervjuet vil være delvis strukturert og dere vil bli bedt om å reflektere rundt et tilfelle dere selv har opplevd i egen praksis. Temaene vil være knyttet til moralske og etiske aspekter i forhold til det å behandle eldre, skrøpelige pasienter med respirator/NIV.

Mulige fordeler og ulemper

Forskning viser at mange leger og sykepleiere, erfarer at respirator/NIV-behandling for eldre, svært skrøpelige pasienter på slutten av deres liv, kan oppleves som et etisk dilemma i klinisk praksis. Dersom du sier ja til å delta i studien, betyr det at du vil få anledning til å dele dine erfaringer omkring temaet med dine kollegaer og oss.

Hva skjer med informasjonen om deg?

Intervjuet vil bli tatt opp på en diktafon og deretter bli skrevet ut i anonymisert form. Det innebærer at ingen opplysninger, vil kunne føres tilbake til deg personlig. Lydfilene fra intervjuene oppbevares på en pc uten internett tilgang og en ekstrakopi vil bli oppbevart i låsbart og brannsikket skap. Når prosjektet avsluttes i 2016, vil lydfilene slettes.

Frivillig deltakelse

Deltakelse i undersøkelsen er frivillig. Du kan takke nei, og uten grunn, når som helst i prosessen trekke deg fra deltakelsen, om du skulle ønske dette. Om du skulle velge å trekke deg fra studien vil alt datamaterialet fra deg bli makulert og ikke benyttet i prosjektet. Ved spørsmål, eller ved ønske om å trekke deg, kan du kontakte stipendiat Heidi Jerpseth, tlf. 990 08 979 eller evt. prosjektleder og veileder førsteamanuensis, Kristin Halvorsen; 922 162 50

Ønsker du å delta i undersøkelsen, vil jeg be deg om å skrive under på samtykke erklæringen nederst på siden. Det medfølger en kopi av denne informasjonen som du beholder. Jeg vil avtale tid for fokusgruppeintervjuet, som passer for dere og avdelingen.

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, Sør-Øst.

Med vennlig hilsen

Heidi Jerpseth

Stipendiat

Samtykke til deltagelse i studien

Jeg er villig til å delta i studien

Sted og dato

Underskrift

Appendix 2: The interview guide focus group sub-study I, Physicians

Demographic data physicians and nurses:

- Gender
- Age
- Experience in ICU or RU

I. Can you recount and discuss a situation where a patient with late-stage COPD were treated with MV or NIV and you felt unsure whether this was the appropriate course of action?

II. How did dealing with this situation make you feel?

III.

- a) Can you please discuss what criteria you use and what influences the decision making process when determining whether severely ill, older patient with COPD should be treated with NIV or MV.
- b) Can you please discuss what you experience as challenging in your daily care of severely ill patients with COPD connected to a treatment with MV or NIV?
- c) Can you please reflect on and discuss who are involved in the decision-making process regarding MV or NIV?
- d) Can you please discuss whether and in what way you experience the collaboration in the decision-making process? I want you to discuss collaboration between you as physicians from different specialties and collaboration between physicians and the nurses.
- e) Can you please discuss how and if information from the patient's GP and/or home based nursing care concerning the patient's history influences the decisions of MV, NIV or palliative care?
- f) You may discuss how you try to gain knowledge of the patient's preferences regarding his or her wishes to be treated on a MV or NIV in severe to very severe stages of the illness. You may also discuss whether patients ever initiate conversations on this issue.
- g) Can you please discuss your thoughts and opinions regarding the patient's participation in making this decision?
- h) Can you please discuss how you think the patient's preferences would impact the decision concerning whether to administer MV or NIV-treatment or not?

Appendix 3: The interview guide focus group sub-study II, Nurses

Demographic data physicians and nurses:

- Gender
- Age
- Experience in ICU or RU

FOCUSGROUP INTERVEIW

I. Can you recount and discuss a situation where a patient with late-stage COPD were treated with MV or NIV and you felt unsure whether this was the appropriate course of action?

II. How did dealing with this situation make you feel?

III.

a) Can you please discuss what you experience as challenging in your daily care of severely ill patients with COPD connected to a treatment with MV or NIV?

b) Can you please reflect on and discuss who are involved in the decision-making process regarding MV or NIV?

c) Can you please discuss whether and in what way you experience the collaboration in the decision-making process? I want you to discuss the collaboration between the nurses and physicians.

d) Can you please discuss how and if information from home based nursing care concerning the patient's history influences the decisions of MV, NIV or palliative care.

e) You may discuss how you try to gain knowledge of the patient's preferences regarding his or her wishes to be treated on a MV or NIV in severe to very severe stages of the illness. You may also discuss whether patients ever initiate conversations on this issue.

f) Can you please discuss your thoughts and opinions regarding the patient's participation in making this decision?

g) Can you please discuss how you think the patient's preferences would impact the decision concerning whether to administer MV or NIV-treatment?



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Appendix 4: Information to patients and written informed consent

SKRIFTLIG INFORMERT SAMTYKKE

Forespørsel om deltakelse i forskningsprosjektet med tittelen:

*Eldre med alvorlig KOLS: Omsorg, kliniske prioriteringer og respirasjonsstøtte
behandling*

Dette er en forespørsel til deg om du er villig til å delta i et forskningsprosjekt om KOLS og respirasjonsstøttebehandling. Studien er en del av stipendiat, sykepleier og høgskolelektor Heidi Jerpseth sitt doktorgradsarbeid ved senter for medisinsk etikk, universitetet i Oslo (UiO). Førsteamanuensis Kristin Halvorsen ved Høgskolen i Oslo og Akershus er prosjektleder og hovedveileder. Professor Per Nortvedt, senter for medisinsk etikk, UiO er medveileder. Prosjektet er finansiert av Ekstrastiftelsen, Landsforeningen for Hjerte og Lungesyke (LHL).

Bakgrunn og hensikt

Forskning og erfaring viser at KOLS er belastende å leve med og at antall pasienter med alvorlig KOLS vil øke i fremtiden. Helsetjenesten trenger mer kunnskap om ulike sider ved å leve med alvorlig KOLS for å gi pasientgruppen best mulig behandling. I forbindelse med

forverring av sykdommen, og /-eller ved blant annet lungebetennelse kan KOLS pasienter ha behov for å få pustehjelp fra en pustemaskin (respirator eller maskebehandling) på sykehus.

Hensikten med denne studien er å undersøke hvordan pasienter med alvorlig KOLS har opplevd å bli behandlet på en pustemaskin. Videre har studien til hensikt å undersøke hvordan du har erfart at helsepersonell (leger og sykepleiere) som følger opp deg og din sykdom har snakket med deg om hvordan dine tanker omkring det å bli behandlet på en pustemaskin.

Vi trenger mer kunnskap om KOLS syke pasienter sine egne tanker og opplevelser om respirasjonsstøtte behandling og hvilke tanker du har i forhold til å være delaktig i, og å bli hørt i beslutninger i denne type behandlingsspørsmål.

Hva innebærer studien?

Studien vil innebære for deg at du er villig til å la deg intervjuet av stipendiat Heidi Jerpseth om dine opplevelser og tanker omkring respirasjonsstøtte behandling. Intervjuene vil foregå ved at undertegnende kommer hjem til deg, dersom du ønsker det, alternativt kan intervjuet gjennomføres på et møterom på sykehuset som du tilhører. Eventuelle reiseutgifter i forbindelse med intervjuene vil bli refundert. Intervjuene vil vare i ca. 45-60 minutter. Dato for intervjuet vil bli når det passer for deg og vil bli avtalt ved at jeg ringer til deg.

Mulige fordeler og ulemper

Dersom du sier ja til å delta i studien, betyr det at du vil få anledning til å snakke om dine erfaringer omkring temaet å være KOLS syk og å bli behandlet med respirasjonsstøtte, samt hvordan du opplever å bli tatt med i beslutninger. Det kan innebære at du får anledning til å snakke med noen om et tema som er viktig for deg. Det kan være at du blir litt sliten av intervjuet. Hvis det skjer så kan vi ta en pause, eller avbryte intervjuet.

Hva skjer med informasjonen om deg?

Intervjuet vil bli tatt opp på en diktafon og deretter bli skrevet ut i anonymisert form. Det innebærer at ingen opplysninger, vil kunne føres tilbake til deg personlig. Lydfilene fra

intervjuene oppbevares på en pc uten internett tilgang og en ekstrakopi vil bli oppbevart i låsbart og brannsikket skap. Når prosjektet avsluttes i 2016, vil lydfilene slettes.

Frivillig deltakelse

Deltakelse i undersøkelsen er frivillig. Du kan takke nei, og uten grunn, når som helst i prosessen trekke deg fra deltakelsen, om du skulle ønske dette. Om du skulle velge å trekke deg fra studien vil alt datamaterialet fra deg bli makulert og ikke benyttet i prosjektet. Ved spørsmål, eller ved ønske om å trekke deg, kan du kontakte stipendiat Heidi Jerpseth, tlf. 990 08 979 eller evt. prosjektleder og veileder førsteamanuensis, Kristin Halvorsen; 922 162 50

Ønsker du å delta i undersøkelsen, vil jeg be deg om å skrive under på samtykke erklæringen nederst på siden. Erklæringen legges i den ferdige frankerte konvolutten som medfølger og sendes til meg. Alternativt så kan du gi underskriften din til hjemmesykepleieren som gir den til meg. Du vil bli kontaktet på det telefonnummeret du oppgir på svarskjemaet av undertegnende innen kort tid.

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, Sør-Øst.

Med vennlig hilsen

Heidi Jerpseth

Stipendiat

Samtykke til deltagelse i studien

Jeg er villig til å delta i studien

Sted og dato

Underskrift

Appendix 5: The interview guide sub-study III, Patients

Demographic data patients:

- Age
- Gender
- Marital status
- Disease years
- NIV or MV last year
- Fixed O₂
- Hospitalized last year

Interview guide Patients with late-stage COPD

1. Identifying the patients' experiences related to their illness.
 - a) How does COPD affect your daily life?
Pain, anxiety, breathlessness, social interaction, the ventilation mask, fixed oxygen
 - b) How do you feel about the future in regard to living with COPD?
 - c) What can you remember from the time period with MV or NIV treatment?
 - d) How did you experience the time following being weaned from NIV or MV?
 - e) What are your thoughts or concerns in regard to possibility of future treatments with MV or NIV?
2. Exploring the patients' experiences about how they perceive their preferences to be taken into account in decision-making processes concerning MV or NIV treatment.
 - a) What are your thoughts regarding your own participating in making decisions concerning your illness and possible treatment?
 - b) In your experience, have you had any conversations with doctors or nurses concerning how you feel regarding MV or NIV treatment?
 - c) Do you feel that you have been consulted and that your opinions are taken into account when decision regarding treatment and care for you are made?
 - d) Have you given any thoughts to what you like to ask or discuss with your doctor or nurse in regard to receiving treatment for your disease?
 - e) At what point would you like such a conversation to take place?

- f) Have you given any thoughts to whether you would like any family members to be present during a discussion concerning treatment with MV or NIV?
- g) How would you feel about having such a conversation with your doctor or nurse?

Papers I-III

