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

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### **Conflict of interest**

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### **Abstract**

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

**Aims and objectives.** The aim of this study was twofold: first, to explore the illness experiences of older patients' with late-stage chronic obstructive pulmonary disease; and second, to develop knowledge about how patients perceive their preferences to be taken into account in decision-making processes concerning mechanical ventilation and /or non-invasive ventilation.

**Background.** Decisions about whether older patients with late stage chronic obstructive pulmonary disease will benefit from noninvasive ventilation treatment or whether the time has come for palliative treatment are complicated, both medically and ethically. Knowledge regarding patients' values and preferences concerning ventilation support is crucial yet often lacking.

**Design.** Qualitative design with a hermeneutic- phenomenological approach.

**Methods.** The data consist of qualitative in-depth interviews with 12 patients from Norway diagnosed with late stage chronic obstructive pulmonary disease. The data were analysed within the three interpretative contexts described by Kvale and Brinkmann.

**Results.** The participants described their lives as fragile and burdensome, frequently interrupted by unpredictable and frightening exacerbations. They lacked information about their diagnosis and prognosis and were often not included in decisions about noninvasive ventilation or mechanical ventilation.

**Conclusion.** Findings indicate that these patients are highly vulnerable and have complex needs in terms of nursing care and medical treatment. Moreover, they need access to proactive advanced care planning and an opportunity to discuss their wishes for treatment and care.

**Relevance to clinical practice.** To provide competent care for these patients, healthcare personnel must be aware of how patients experience being seriously ill. Advanced care planning and shared decision-making should be initiated alongside the curative treatment.

### **What does this paper contribute to the wider global clinical community?**

Chronic Obstructive pulmonary Disease (COPD) is currently the fourth leading cause of death in the world. It is projected to be the third leading cause of death by 2020.

- This paper provides understanding and knowledge regarding the patients' experiences of being in late-stage of COPD.
- This paper explores how patients with severe COPD experienced involvement in decision-making regarding noninvasive and mechanical ventilation.
- This paper contributes to a broader understanding of how nurses can comfort and care for the patients in the late-stages of COPD.

**Key words:** Chronic obstructive pulmonary disease, patients' voice, decision-making processes, patients' participation, nurses responsibility

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

## Introduction

Chronic obstructive pulmonary disease (COPD) is an incurable, progressive illness characterized by airflow obstruction and respiratory failure, in addition to a high degree of suffering, impaired functional capacity, poor quality of life, and eventual death (Patel *et al.* 2012). Most of the patients suffering from this disease will occasionally experience acute exacerbations. Acute exacerbation can be life-threatening, and patients with severe COPD are likely to receive intensive care during the later stages of the disease, including mechanical ventilation (MV) and noninvasive ventilation (NIV) (Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2015). NIV is a method of providing ventilatory support via a mask without an endotracheal tube. This treatment improves gas exchange and is increasingly used as an option of last resort for patients who are dying of respiratory failure (Azoulay *et al.* 2011). Research highlights that that 20-30 % of patients with COPD who are treated with NIV also need MV treatment once or more (Goodridge *et al.* 2009). However, uncertainty remains both as to whether NIV relieves subjective dyspnea and regarding the extent to which patients experience the treatment as an extra burden in an already stressful situation (Smith *et al.* 2012, Torheim & Gjengedal 2010).

Even though the prognosis is about the same for COPD as it is for lung cancer, COPD patients rarely receive planned palliative and end- of- life care (EOLC) (Janssen *et al.* 2013, Lal & Case 2014). Relatively few studies have examined patients' preferences with regard to care during the later stages of COPD (Bereza *et al.* 2015, Momen *et al.* 2012), and little is actually known about how patients experience receiving NIV (Smith *et al.* 2016, Smith *et al.* 2015, Sorensen *et al.* 2014). One area of concern therefore is whether patients have more interventions like NIV- treatment and hospital admissions towards the end of their lives than they want or than are appropriate (Carlucci *et al.* 2016, Dretzke *et al.* 2015). Improved understanding of the patient experiences can help caregivers to better respond to the complex

interplay of evidence, clinical need and patient preference. This is especially important since the one-year survival rate for hypercapnic respiratory failure following NIV is ~50 % (Chu *et al.* 2004, Titlestad *et al.* 2013). This mortality rate highlights the challenges health care providers faced when it comes to prognosis and decision- making regarding treatment options like NIV, and studies show that there is a wide variation in intubation and intensive care admissions decisions among physicians (Gaspar *et al.* 2014, Jerpseth *et al.* 2016a). This amplifies the need for a clear discussion about decision- making when the patient is in a stable phase. Advanced care planning (ACP), which involves patient-clinical communication about end-of-life care, can improve outcomes for patients and their families (Patel *et al.* 2012). This can include discussion of individual's understanding of their diagnosis and prognosis, any concerns, and preferences and wishes for care and treatment in the future (MacPherson *et al.* 2013). Healthcare personnel in Norway are also legally bound to ensure that patients are informed and involved in making decisions about their treatment options and goals related to the development of their illness (The Patient and Users Rights Act, 1999).

This paper investigates how older Norwegian patients with late-stage COPD experience their illness and receiving NIV or MV for exacerbation, as well as how they perceive healthcare personnel's ability to communicate with them regarding their treatment preferences, including treatment options like MV or NIV.

## **Background**

The disease trajectory for COPD patients involves years of chronic illness with periods of exacerbation and acute ventilatory failure. More than 60% of patients hospitalized due to acute exacerbation of their COPD are readmitted within a year. The need for repeated hospitalization is associated with marked reductions in patients' quality of life, as well as higher mortality rates (GOLD 2015).

Reduction of quality of life is often characterized by physical symptoms like breathing problems, exhaustion and pain, compounded by comorbidity and psychological distress, including anxiety, depression and social isolation (Disler *et al.* 2014, Janssen *et al.* 2015, MacPherson *et al.* 2013, Patel *et al.* 2012). Breathlessness is a common, complex symptom of COPD, with a prevalence of up to 94% in late- stage COPD (Blinderman *et al.* 2009, Currow *et al.* 2010). Treatment of late- stage COPD is largely focused on reactive symptom control of acute exacerbation instead of planned palliative care.

Treatment with NIV plays a definite role in the management of acute hypercapnic respiratory failure and acidosis and the use of NIV treatment has been shown to reduce rates of both intubation and complication (Mas & Masip 2014). However, mask treatment is often challenging for patients as it can exacerbate breathlessness, anxiety, claustrophobia, thirst, exhaustion, sleeplessness, communication difficulties, and delirium, and the mask can create pressure, heat and noise (Torheim & Gjengedal 2010). In the later stages of the disease, treatment with NIV might also prolong suffering, not to mention the dying process itself. Legal regulations in Norway and most other Western countries emphasize a patient's right to be heard and to participate in decisions about medical treatment and nursing care. Hence, patients with severe COPD have a legal right to be involved in making decisions about their treatment options and about goals related to the development of their illness. Decisions should be based on interdependence and trust between patients and their caregivers (Norwegian Directorate of Health 2012). In the medical context, trust refers to the expectation of patients that caregivers will perform their responsibilities with a certain level of competence and responsibility and will make patients' welfare their highest priority (Carter 2009). Implicit in these criteria are the further expectations that all responses will be sensitive and caring, and that caregivers will encourage open and honest communication (Skirbekk & Nortvedt 2011).

It is reasonable to expect healthcare personnel to act appropriately and in the best interests of their patients (Mechanic & Meyer 2000). However, studies have shown that healthcare personnel rarely engage in dialogue with patients with COPD about decisions regarding end-of-life care (EOLC), even though most patients seem to want to participate in these decisions (Carlucci *et al.* 2016, Philip *et al.* 2012, Spathis & Booth 2008). Limiting intensive treatment (NIV or MV) for patients with serious deterioration of COPD is closely associated with EOL- decision-making and EOLC. Decisions about whether an elderly patient with late- stage COPD will benefit from NIV or MV treatment or whether the time has come for palliative treatment are complex, and must be based on individual reasoning in each particular situation.

Ethically, as well as legally, knowledge regarding patients' values and preferences, along with adjusted patient information, is critical when making EOL decisions. When a patient's condition is stable following an acute episode, discussion about that patient's long-term goals in the context of end-stage illness can be initiated readily, although it very rarely is (Gaspar *et al.* 2014, Jerpseth *et al.* 2016a, Jerpseth *et al.* 2016b). Since patients with severe

COPD rarely have planned palliative care, older patients with severe COPD often die in hospital during a period of acute exacerbation without having had the opportunity to express their choices or wishes regarding EOLC (Jerpseth *et al.* 2016b, Lal & Case 2014). Lack of knowledge concerning patients' preferences may also lead to under- or overtreatment (Halvorsen *et al.* 2009).

Providers are increasingly emphasizing ACP for patients with COPD. ACP may be a way to prioritize and coordinate health care services to meet their needs. Rather than pressuring patients to make binding decisions about treatment preferences, these discussions should, allow them to be involved in decision about their care (Patel *et al.* 2012).

## **The study**

### **Aim**

The aim of this study was twofold: first to explore the illness experiences of older patients' with late-stage COPD; and second to develop knowledge about how patients perceive their preferences to be taken into account in decision-making processes concerning MV or NIV-treatment.

## **Methods**

### **Design**

To explore how older patients with late- stage COPD experience being seriously ill and perceive their involvement in decision-making, we applied a phenomenological experience-based perspective and a hermeneutic interpretation-based perspective. The purpose of phenomenological research is to acquire a deeper and richer understanding of people's experiences (Van Manen 1997). Hermeneutics is about how to achieve understanding and how phenomena have to be interpreted to be understood (Brinkmann & Kvale 2015). Individual interviews were conducted to understand the world from the participants' point of view, to unfold the meaning of their experiences, to interpret their lived world as related to

being seriously ill, and to determine the extent to which they were involved in relevant decision-making processes.

This study is a part of a larger qualitative research project on decision-making processes regarding NIV and MV for older patients with late-stage COPD. The research project includes two focus group studies with health care professionals, and one study, using individual interviews with patients [this paper] (Jerpseth *et al.* 2016a, Jerpseth *et al.* 2016b).

### **Recruitment and Participants**

Nurses who worked in the hospitals' outpatient clinics made the initial contact with the patients and recruited them. The patients received written and oral information about what participation in the interviews entailed, including the length of the interview, the place where the interview would take place, and the aim of the study. They were also informed about confidentiality and reminded that they had the right to stop for any reason. One week after the initial contact was made, the first author (HJ) telephoned the patients who had indicated a willingness to participate in the study and provided them with further details about the project. All the invited patients agreed to participate in the study. Written, voluntary informed consent was obtained from all patients prior to data collection.

Twelve patients from one university hospital and two district hospitals were recruited for this study. The sample size was determined following Brinkmann and Kvale's (2015) recommendation to interview as many informants as necessary to get the desired information (p. 148). After twelve patient interviews, the data were saturated and no new information emerged.

The inclusion criteria were as follows: older patients ( $\geq 64$  years old) with late stage COPD (GOLD III-IV). Patients classified with GOLD stages III- IV, have obstruction ( $30\% \leq FEV_1 < 50\%$  predicted), presence of comorbidities such as commonly cardiovascular disease, osteoporosis, malignancies, current nature and magnitude of patient's symptoms (GOLD, 2015). The patients' included had episodes of serious exacerbation that resulted in hospitalization and MV and/or NIV treatment at least once during the previous year. All patients could write and speak Norwegian and were in possession of their cognitive faculties. None of the patients was hospitalized during the interviews.



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Patients diagnosed with severe depression and/or anxiety, cognitive impairment and those who for other reasons that were not able to give informed consent were excluded from the study. The demographic and medical characteristics of the participants are detailed in **Table 1**.

## **Ethics**

Permission to conduct the interviews, as well as to collect and store sensitive data, was obtained from the institutional review boards of the participating hospitals and the Regional Committee for Medical Research Ethics (REK) (ref. 2012/618). All information was stored confidentially. The analyses were carried out using de-identified transcripts. The participants all gave their written, voluntarily, informed consent. Because the participants were vulnerable, the interviewer paid particular attention to their emotional and physical reactions to the interview questions. When approving the study, the ethical committee noted that the interviewer (HJ) was an experienced nurse, who was able to make judgments about the informants' condition during the interview. The interviewer had the opportunity to call the hospital policlinic nurse, who knew the patients well, if there was any cause for worry.

## **Data collection**

Data were collected from January to June 2013, using a semi-structured interview guide (Appendix 1). The twelve interviews were conducted in person by the first author (HJ) either in the participant's home ( $n=10$ ) or in a nursing home ( $n=2$ ). The mean duration of the interviews was one hour.

Each interview started with the participant being asked to describe their experience of being a patient with severe COPD and their perceived involvement in decision-making. The questions were asked openly to encourage the participants to share their stories (e.g., how do you feel about being involved in decisions about your treatment in the future?) The structure and meaning of the text were then jointly produced by the participant and the researcher (Brinkmann & Kvale 2015). The interviews were guided by the research questions, but participants also followed up on the questions, often giving important information spontaneously. To avoid leading questions, which can threaten the trustworthiness of qualitative interview data (Brinkmann and Kvale, 2015), the questions were formulated to avoid yes or no answers. Answers were also followed up by open questions such as 'Can you

tell me some more about this?’ The participants’ statements were validated by asking questions like ‘Do I understand you right when...’

All the interviews were audiotaped and transcribed verbatim by the first author, and no identifiers were included.

### **Data analysis**

All authors were involved in the analysis. In analyzing the data, the researchers switched back and forth between the three interpretative contexts described by Brinkmann and Kvale (2015): self-understanding, critical commonsense understanding, and theoretical understanding. Self-understanding corresponds to participant’s own understanding of the meaning of their statements; critical commonsense understanding relates to how the authors interpret and critically question the data material; theoretical understanding is based on research into living conditions and experiences of living with severe COPD, decision-making, autonomy, and trust, as well as on international and national guidelines and regulations (Beauchamp & Childress 2013, GOLD, 2015, Norwegian Directorate of Health 2012).

Three of the authors (KH, PN, and HJ) have significant experiences in nursing, ethics and qualitative research, while VD is a very experienced researcher and physician with expertise in anesthesiology. The first author (HJ) listened to all the audio files twice and transcribed seven of the interviews, while an experienced typist transcribed the other five interviews. All authors then read the transcribed interviews to get a sense of the whole before discussing the material and agreeing upon the three main-themes and four sub-themes. The coding process was data-driven, and involved organizing the text according to codes developed from the data itself in an inductive process (Brinkmann & Kvale 2015).

### **Findings**

The participants were aged between 63 and 87 years old. There were seven women and five men, all of whom had been diagnosed with severe COPD.

The first two main themes are associated with the patients’ experiences of being seriously ill and their experiences of being treated with NIV. The third main theme includes findings related to the patients’ experiences of inclusion in decision-making processes (see **Table 2**).

## Loneliness of the illness

The participants reported a high symptom burden in addition to functional impairments. All the participants described their quality of life as very poor, reporting difficulty of breathing, pain, anxiety, social isolation, and loneliness. They described their lives as very unpredictable, with their health changing on day-to-day basis. They were most frightened by episodes of exacerbations, and they felt like they were living on borrowed time.

### *Fragile life of breathlessness, pain, and anxiety*

All the participants felt that their lives had become increasingly fragile. The impact of breathlessness was significant and it pervaded their daily life. Their main worries, however, were unpredictable episodes of breathlessness and the acute worsening of cough and sputum production that occurred several times a day. Most participants reported feelings of panic when they experienced what they described as ‘air hunger’. They experienced that anxiety and breathlessness were intertwined. Feelings of panic and breathlessness reinforced each other and lead to a vicious cycle wherein the patients felt they were losing control. Some patients reported a close relationship between anxiety and perceived breathlessness and the resultant admission or readmission to hospital. They were constantly challenged by their reduced health, their increasingly limited choices, and the fear of dying.

Having ‘hunger for air’ gives me a feeling of panic. I cannot bear to be alone because I have a strong feeling that I am going to die (M 70).

Several patients complained about pain in the back, chest, and shoulder region, which became worse during episodes of heavy coughing.

I have terrible pain in my lower back because of the osteoporosis. I have about three fractures. I must say that my quality of life is about zero (F 82).

### *The ventilation mask – a bother and a life buoy*

All the participants had been treated with NIV at least once during the previous year following hospitalization. They clung to the hope that the NIV treatment would help them through what they experienced as a respiratory crisis. The participants described the mask as tiresome, unpleasant and a bother. On the other hand, they expressed an appreciation for

having the opportunity to use the mask as a 'life buoy' - a symbol of hope and survival-even when there was no prospect of healing. Some of them experienced feeling a lack of control over their own situation because they were dependent on external support to stay alive.

It is terrible to use the mask. It is painful and claustrophobic. I do not have any other options unfortunately because a part of me wants to live a bit longer (F 67).

Six participants had been treated with MV in addition to NIV-treatments during previous year. All of them referred to this experience as being very unpleasant, and they expressed that they would not undergo such treatment again. However, none of them had discussed this matter with healthcare personnel.

Last time I was hospitalized, I was treated with MV. I felt so small, afraid, and alone. I will never do it again, I would rather die (F 63).

#### *Social isolation and loss of previous way of living*

The patients in this study were all in a late-stage of their illness, and most of them had suffered from COPD for many years (mean = 11 years). The COPD had gradually worsened and limited their lives in fundamental ways. Eight of the twelve participants used fixed oxygen at home, which they described as a practical challenge that left them housebound.

Breathing is one of the basic needs, but I cannot do it without help. So my life has become very fragile and I am scared (M71).

Participants mentioned the disease itself, especially the breathlessness, as the reason they lacked energy. When comparing their current situation with what their lives used to be like, they described a feeling of loss. To avoid exercise-induced breathlessness, they stayed away from activities that trigger breathlessness and thus avoided exertion. All the participants experienced that their physical activity was impaired by breathlessness. As a result, they all experienced a deterioration of functional and social status. Every action had to be planned and normal activities such as dressing, showering, and preparing a meal were all described as tiresome. In this scenario, their social lives were reduced to a minimum.

I cannot go on holiday any more. Nor play with my grandchildren. I have no energy, and I know things will get worse. My social network has disappeared, and with it, my whole life (M 70).

The patients also expressed feeling lonely, describing the feeling as one of endless hopelessness. They talked about feelings of grief and loss that arouse from their daily struggles and suffering. Some of the participants described not having anyone to talk to about their worries and grief caused by their loss of their former way of living.

Sometimes I go through the day without talking to anybody. These days I look forward to the evening, since then I take my sleeping pill and escape from it all (F 65).

### **Lack of empathy and trust**

The participants reported little memory of their most recent hospital admissions for acute exacerbations, including intensive care admissions and ventilation support. Some of them described 'waking up' on NIV several hours or days after hospitalization. They described this situation as creating a lack of control and a sense of vulnerability. Several participants expressed that they no longer had confidence that anyone would ask them about their own feelings concerning the severity of the disease.

I do not remember anything from the first days at the hospital. Afterward I could not stop thinking that I could have died. These thoughts frighten me, they are destructive, and they are very difficult to live with. Do the doctors want to try to save me next time? These thoughts are especially difficult during the night and they make it hard for me to sleep (F 64).

When asked about their general practitioner's (GP) role in their treatment and care, none of the participants reported having had a conversation with their GP regarding their future care and treatment options. The participants experienced no interactions with healthcare personnel, in either municipal or specialist healthcare settings, concerning existential and physical matters where openness, honesty, and empathy were displayed.

My life will soon end. It will have been a short life, but I have to be thankful for every day. I have never talked to any professional or family member about death, or dying. I do not want to have that kind of conversation because I am afraid I will start crying

and I believe that neither the doctors nor the nurses have the time or willingness to comfort me. My husband does not want to talk about things like death and dying. It is better not to say anything (F 64).

### **Ignored and excluded from making decisions about care and treatment**

The participants reported different experiences of receiving information. Some stated that they did not receive any information, while others described having trouble understanding the information they were given. Some of them expressed having difficulty understanding the relationship between increased attacks of breathlessness and the deterioration of their COPD. The participants were not able to remember whether anyone had ever asked them if they wanted to use NIV, nor whether had they discussed the burden versus benefit of the treatment with either their physicians or their nurses. They had not been presented with alternative treatment or care options, such as palliative care.

I do not know why I have to use the mask, maybe there is pollution in my blood. The mask is the doctor's decision. Nobody asked me (M 70).

Often participants experienced being presented with a decision already taken by the physicians with no room for discussion afterwards.

Nobody told me afterwards what had happened, but I think I was about to die. The doctor told me subsequently that I would not receive that lifesaving help again. I do not know what that means, but I think they do not want to help me and so will let me die next time I have an exacerbation. 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 (F 64).

### *Talking about the prognosis, death, and dying*

Several participants wanted more information about how their disease would progress. Nevertheless, they found it difficult to raise these questions themselves, mostly because of their high symptom burden and experiences of being ignored, not listened to, or talked to in a way that implied they did not understand the message. However, the participants differed in

how much information and how many conversations they wanted to have about difficult topics

Nobody ever talked to me about the disease or the prognosis. Last year I was hospitalized ten times; I tried to talk to the doctors and the nurses, but nobody seemed to want to have such a conversation, so I have given up and stopped asking (M 68).

Two of the participants expressed that 'not knowing' was for the best.

I do not want to talk about death and dying. It makes me afraid (M 74).

Some of the participants mentioned emotional and existential concerns related to loss of meaning and hope, as well as fear of death and the dying process, especially the frightening idea of being suffocated.

I do not think I will live for much longer, but no one has told me that my life will soon be over. Death itself is not frightening, but the idea of suffocating is. I have tried to ask a physician, 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 (F 65).

Two of the participants took it for granted that the physicians were the ones who should decide on the course of the treatment, and they were confident that the doctors were doing their best. The other ten wanted to play a part in the decision-making process. They all expressed that their care and treatment options depended on the physicians' estimation of their conditions, without any actual involvement on their part. Lacking control over their symptoms and not knowing what would happen next made them feel helpless and powerless in what they perceived as vital decision- making.

In summary, the participants described negative experiences and feelings of unhappiness. However, some patients gave the impression of having somehow come to terms with both their illness and their fate.

## **Discussion**

The aim of this study was to explore the illness experiences of older patients' with severe COPD and to develop knowledge about how patients perceive their preferences to be taken into account in decision-making processes concerning MV/NIV treatment.

The participants in this study described life with late-stage COPD as fragile, burdensome, and frequently interrupted by unpredictable and frightening exacerbations. These findings are consistent with those of other research (Janssen *et al.* 2015, MacPherson *et al.* 2013, Patel *et al.* 2012). Treatment with NIV brought forth a wide range of feelings and tension. The participants described the sensation of this treatment as being at the threshold between life and death. These experiences correspond with research that describes how patients adapt to NIV (Haugdahl *et al.* 2015, Smith *et al.* 2012, Sorensen *et al.* 2014, Torheim & Kvangarsnes 2014). In contrast to the findings in those studies, where the results showed that patients perceive healthcare personnel as trustworthy, our findings showed that some of the patients did not have confidence that the health care personnel would act in their best interest. These feelings of distrust implied powerlessness and disempowerment for patients in our study.

The empirical data showed that the majority of participants wanted information regarding their prognosis and future disease management, which corresponds with other findings (Bereza *et al.* 2015, Philip *et al.* 2012). However, the most striking finding of our research was the patients' unmet need for care and communication regarding their experiences of existential worry. Some of the participants did not talk to anyone about their worries and grief. Their fear of what dying might be like and their feelings of hopelessness and loneliness related to their illness were neither noticed nor addressed. All the participants experienced that neither their nurses nor their physicians invited them to participate in a dialogue where openness, consolation, and hope for relief were themes. Instead of dialogue, some participants described a one-way flow of information where they were informed, 'what the physician thought was in their best interest' which left them feeling helpless about their worries and questions. While this lack of communication might reflect a lack knowledge about the importance of taking patient preferences seriously, such a conclusion seems unlikely considering these patients' obvious vulnerability.

These patients' experiences of the healthcare personnel's paternalistic attitude regarding treatment and care corresponded with our findings when we interviewed physicians and nurses who care for COPD patients in both pulmonary and intensive care wards (Jerpseth *et al.* 2016a). Moreover, the nurses, who often knew the patients well, rarely took part in treatment-related decisions, nor did they communicate with the patients about themes related



to their treatment and care options. Such lapses in communication may lead to further weakening of the patient's voice in decision-making (Jerpseth *et al.* 2016b).

Late- stage COPD implies a need to consider EOLC in care planning. Guidelines and healthcare regulations highlight that care at the end of life should be based on an agreement between patients, their families, and healthcare professionals in order to ensure the best quality of care corresponding to the patients' values and preferences (GOLD, 2015, Norwegian Directorate of Health 2012). However, studies have shown that physicians find it challenging to communicate with COPD patients (Janssen *et al.* 2012). The prognostic uncertainty associated with end-stage COPD- combined with the desire to maintain hope, the fact that patients are in acute need of help, and the assumption that information can cause harm to patients, prevents healthcare personnel from initiating necessary conversations. Another important consideration is the difficulty of determining when to raise the issue of EOLC, together with the fact that proactive palliative care for COPD patients is still not well organized (Carlucci *et al.* 2012).

Research has shown that elderly patients with COPD seldom express their desire to receive information and to be involved in decision- making regarding their treatment (Lowey *et al.* 2013). This corresponds with our findings. The patients' silence might be interpreted as a lack of desire to discuss their prognosis, treatment, and goals with their clinicians in an attempt to use displacement behaviour as a coping strategy. However, patients' silence might also be related to their poor physical condition, their acute situation when hospitalized, and their feelings of being ignored.

The interviewed patients experienced cycles of intermittent exacerbations along with declining health and decreasing functional status. When they were hospitalized, they received medical assistance in the form of MV and NIV treatment that eased their breathing problems in the 'here and now'. The patients lacked clarity on and understanding of both the course and prognosis of COPD, and the rationale behind using MV and NIV. They had no or very limited knowledge about any other treatment or care options that might have eased their suffering. The patients were not offered palliative treatment with oxygen and opioids, despite robust evidence of this treatment's effectiveness in the management of breathlessness (Boland *et al.* 2013, Varkey 2010). Treatment with NIV plays a definite role in the management of acute hypercapnic respiratory failure and acidosis, but its usefulness in

relieving dyspnea at the end of life has still not been adequately documented (Mas & Masip 2014, Smith *et al.* 2012).

In order to make informed decisions about their own care, patients must be able to understand the information that is given to them and freely communicate their wishes and values to caregivers (Beauchamp & Childress 2013). The participants in our study had poor recollection of their acute hospital experiences. Due the acute and serious nature of these hospitalizations, the patients had a limited ability to partake in complex discussions, and it is therefore reasonable to believe that their decision-making capacity was reduced. However, none of the participants had talked to their providers about prognosis, goals for treatment, and care when their condition permitted such a dialogue. ACP with regular discussions in the non-acute phases of the disease may be one way to create dialogue with patients, their next of kin and health care personnel. The themes addressed in these discussions should be prognosis, goals for treatment and care (MacPherson *et al.* 2013, Patel *et al.* 2012).

Studies have shown that patients with chronic illnesses consider their physician's involvement in their illness to be important for establishing trust in the healthcare system (Skirbekk *et al.* 2011). The relationship between patient and healthcare personnel is based on the two parties' having complementary roles: patients are in need of help and care while the healthcare professionals are able to provide help and care. Such relationships are based on trust, and the paradox of trust is that it cannot grow without one party first taking the risk of placing its trust in the other (Carter 2009). The patients in this study experienced a lack of familiarity and interaction with both the nurses and the physicians, making it difficult for them to establish trust.

Patients with COPD are especially vulnerable because of their life-threatening illness, their dependency on healthcare personnel, and their asymmetrical knowledge of medicine. In acute situations, patients are forced to take the risk of trusting in the healthcare personnel's competence. The patients in the study needed to believe that the healthcare personnel were willing to respond morally to their suffering and vulnerability, for example, by bringing up ACP.

When patients with COPD are in remission, their gradual independence will generally render them capable of choosing whether or not they want to share their values and preferences regarding EOLC. However, because these issues are sensitive and highly emotional, patients might choose to remain silent rather than putting themselves at risk of being rejected or ignored. This attitude is reinforced by the healthcare system, on which they

increasingly depend but which has failed to effectively advocate for their needs. The choice to remain silent may weaken patients' autonomy, and they consequently may be viewed with a paternalistic attitude and excluded from participating decision about their own health condition.

### **Limitations of the study**

As this is a qualitative study, the number of participants is relatively small, and all the data were collected in one country in Western Europe. During the interviews, some participants talked about their experiences related to the theme of being seriously ill and their feelings of vulnerability for the first time. Talking about a theme for the first time might reinforce patients' sense of having been deprived of the opportunity to share their thoughts, and might increase their desire to receive comfort and care. The participants focused much on the negative experiences in their answers. One limitation of this study is that we did not ask the participants specifically about positive experiences with health care. Having done so could have resulted in more nuanced answers; such questions should be a focus of further research.

This study is a one of three sub-studies dealing with the same themes, namely decision-making processes regarding older patients with late-stage COPD. We had already interviewed nurses and physicians who work daily in respiratory and intensive care units. These interviews highlighted complementary aspects of the same phenomenon (Jerpseth *et al.* 2016a, Jerpseth *et al.* 2016b), thereby allowing us to triangulate our findings (Creswell 2012). At the same time, our preconceptions were influenced by the previous research demonstrating that the physicians and the nurses did not consider it important to include patients in decision-making processes. However, we aimed to maintain a balance between staying close to the theme as an essential part of the generating of understanding and striving to be sensitive to unavoidable preconceptions, which involved reflexive objectivity (Brinkmann & Kvale 2015).

### **Relevance to clinical practice**

For health care personnel to be able to provide competent care to patients with late-stage COPD, it is essential that they understand how these patients' experience their illness. Our most striking finding was that patients had unmet needs for both care and communication

regarding their grief and existential worries. If these needs are to be met, it is necessary to increase awareness among healthcare personnel about the challenges patients face. Healthcare personnel have an obligation to ensure that patients are informed about the nature and prognosis of their disease, as well as to listen to patients' needs, values, and preferences. This requires the healthcare system to shift the goal of disease management from prolonging survival to providing palliative care and to accommodate patients' need to participate in decision-making processes. Advanced care planning and shared decision-making for patients with late stage COPD should be initiated, including discussion between patients and their care providers on how the condition might develop in the future.

## **Conclusion**

Our findings indicate that patients with COPD are highly vulnerable and hence have complex needs regarding care and treatment. This study indicates that neither their need for adequate information about prognosis and diagnosis, nor their needs to be included in decision-making processes are met. These patients are in need of proactive palliative care planning that should start early in the disease alongside curative treatment. Because unpredictability is a major challenge of COPD, they need to know what they can expect in terms of the involvement, compassion, and care from both physicians and nurses according to their situation. Finally, although this research provides no evident answer, it would be interesting to know if the observed lack of moral responsibility among healthcare personnel resulted from a lack of moral perception, a lack of concern for patients' wellbeing or both. Being able to see what is at stake for another person- the patient, in this case- is recognized in moral theory as a basic requirement of moral action and is a basic requirement of moral action and responsibility (Blum 2009, Nortvedt 2016, Vetlesen 1994). The failure to respect patients observed in this study goes beyond current bioethical concerns about respecting patient autonomy, demonstrating instead a lack of receptivity to patient experiences-that may be call a lack of moral perception. It is noteworthy that the vulnerability that is so apparent in these patients' stories is not recognized by the professionals in charge of their care. It will be important for future research to also investigate what causes such failures of moral perception.

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## Conflict of interest

The authors have no conflict of interest to declare.

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**Table 1** 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	LA	W	D	D
Disease years	7	5	15	10	8	5	10	10	14	20	15	15
NIV/MV previous year	M	N	M	M	M	N	N	N	N	N	M	M
Fixed O <sub>2</sub>	O <sub>2</sub>	O <sub>2</sub>	-	O <sub>2</sub>	O <sub>2</sub>	O <sub>2</sub>	-	O <sub>2</sub>	-	O <sub>2</sub>	-	O <sub>2</sub>
Hospitalized previous 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.

**Table 2** Main themes

Main themes	Sub-themes
<b>Loneliness of the illness</b>	<i>Fragile life of breathlessness, pain, and anxiety</i>  <i>The ventilation mask – a bother and a lifebuoy</i>  <i>Social isolation and loss of previous life</i>
<b>Lack of empathy and trust</b>	
<b>Ignored and excluded from making decisions about care and treatment</b>	<i>Talking about the prognosis, death, and dying</i>