

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

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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. Decision whether the old patient with late stage chronic obstructive pulmonary disease will benefit on noninvasive ventilation treatment or time has come for palliative treatment is complicated both medically and ethically. Knowledge regarding patients' values and preferences concerning ventilation support is crucial, although often not known.

Design. Qualitative design with a hermeneutic- phenomenological approach.

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

Results. The participants described a fragile and burdensome life, which was frequently interrupted by unpredictable and frighten exacerbations. They lacked information about their diagnosis and prognosis and were not included in decision-making processes regarding treatment with noninvasive ventilation or mechanical ventilation.

Conclusion. Findings indicate that the patients are highly vulnerable and hence have complex needs regarding care and treatment. This study indicates that neither patients' need for adequate information about prognosis and diagnosis, nor their needs to be included in decision-making processes are met.

Relevance to clinical practice. Identifying the patients' experiences of being seriously ill is essential to health care personnel in order to give patients competent care. Advanced care planning and shared decision-making should be initiated.

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

Chronic Obstructive Pulmonary Disease is currently fourth leading cause of death in the world. It is projected to be the third leading cause of death in 2020.

- This Paper gained more understanding and knowledge regarding the patients' experiences of being in late-stage of COPD.
- This Paper explored how patients with severe COPD experienced to be involved in decision-making regarding noninvasive and mechanical ventilation.
- This Paper contribute a wider understanding of how nurses may comfort and care for the patients in the late-stage of COPD.

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

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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. An acute exacerbation is 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, it improves gas exchange, and this treatment 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 as to whether NIV relieves subjective dyspnea and to what extent the 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). An area of concern therefore is whether patients have more interventions like NIV- treatment and hospital admission towards the end of their lives than they want or are appropriate (Carlucci *et al.* 2016, Dretzke *et al.* 2015). Improved understanding of the patient experiences can help caregivers better respond to the complex interplay among 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 provider faced when it comes to prognosis and decision- making regarding treatment options like NIV, and studies show that decisions to intubate and admit to intensive care units vary considerably between individual 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. Healthcare personnel 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 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 in late- stage COPD is directed largely at reactive symptom control on 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 intubation and complication (Mas & Masip 2014). However, mask treatment may still be a challenge 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 decision-making regarding 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 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 those who care for them will perform their responsibilities with a level of competence and responsibility aimed at making patients' welfare their highest priority (Carter 2009). Implicit in these criteria are 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 COPD patients regarding end-of-life (EOL) decision-making processes, even though most such patients seem to want to participate in decision-making related to their EOLC (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, alongside 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 could be readily initiated, 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).

ACP is increasingly emphasized for patients with COPD, and for patients with severe COPD it may be an important approach to prioritizing and coordinating health and care services to meet the best interest of the patients. ACP represents a process of open discussion between patients and their care providers about how their condition may affect them in the future (MacPherson *et al.* 2013). This includes discussions concerning the patients' understanding of their diagnosis and prognosis, as well as any concerns and preferences regarding care towards end-of-life. 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 of 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 professional, 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 should take place, the aim of the study, confidentiality, the right to stop if they felt it burdensome or wanted to stop for other reasons. One week after the initial contact was made, the first author (HJ) telephoned the patients who had indicated a willingness to partake in the study and provided them with further details about the project. All the invited patients agreed to participate in the study. 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 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. All patients could write and speak Norwegian and were all possession of their cognitive faculties. None of the patients were hospitalized during the interviews. 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.

Data collection

Data were collected from January to June 2013, using a semi-structured interview guide (Appendix 1). The twelve interviews were conducted face-to-face 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 focusing on encouraging 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 differed. Some participants talked more freely and openly about their experiences, while others gave only short answers to the questions asked. All the interviews were audiotaped and transcribed verbatim by the first author.

Data analysis

The data generated in the study was analysed in three interpretative contexts described by Brinkmann and Kvale (2015) (1) self-understanding, (2) critical commonsense understanding, and (3) theoretical understanding. These 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 between the levels. In the context of self-understanding, the data was interpreted as a condensed form of a participant's own understanding of the meaning of their statement. Critical commonsense understanding went beyond what was actually said, since the meaning of what was said was interpreted by the authors, who critically questioned the data material. Theoretical understanding stems from research into living conditions and experiences of living with severe COPD, decision-making, autonomy, and trust, as well as international and national guidelines and regulations (Beauchamp & Childress 2013, GOLD, 2015, Norwegian Directorate of Health 2012). First, the first author listened and re-listened to all the audio files. All authors then read the transcribed interviews. In carefully reading the transcripts, we got a sense of the whole before we discussed and agreed upon the three main-themes and four sub-themes. The coding process was data-driven, and involved organizing the text in accordance with the 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 theme represents those 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, as manifested in difficulty of breathing, pain, anxiety, social isolation, and loneliness. They described life as very unpredictable, with their health changing on day-to-day basis. The episodes of exacerbations were the most frightening and they felt like they were living on borrowed time.

Fragile life of breathlessness, pain, and anxiety

All the participants felt that their life 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 lifebuoy

All the participants had been treated with NIV at least once during the last 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’, which is a symbol of hope and staying alive, although there is no prospect of healing. Some of them experienced a feeling of lacking 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 life

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).

The disease itself, especially the breathlessness, was described as the reason for their lack of energy. The participants described this feeling as one of loss compared to what their

lives used to be like. To avoid exercise-induced breathlessness, they stayed away from things 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 being lonely, describing it as a feeling of endless hopelessness. The patients talked about their grief and loss which arose from their daily struggles and suffering. Some of the participants described that they did not have anyone to talk to about their worries and grief regarding their experiences of losing the life they used to live.

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. The participants 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 communicate with them regarding 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 if anyone had ever asked them if they wanted to use NIV, nor had they discussed the burden versus benefit of the treatment with either their physicians or 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 ten others 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. The lack of 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.

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 a fragile and burdensome life with late-stage COPD, one that was 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 included a wide range of feelings and tension. The participants described this sensation 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 have the perception of being able to trust in health care personnel, 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 seen nor addressed. All the participants experienced that neither the nurses nor the physicians invited them to participate in a dialogue where openness, consolation, and the promotion of hope regarding illness relief were themes. Instead of such a dialogue, some participants referred to one-way information where they were informed, 'what the physician thought was in their best interest' which left them feeling helpless about their worries and questions. The lack of communication might be lack of knowledge about the importance of taking patient preferences seriously. However, this is strange because of 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. This may lead to further weakening of the patient's voice in decision-making (Jerpseth *et al.* 2016b).

Late- stage COPD implies thinking of 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, coupled 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 point 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 for 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 order to use displacement behaviour as a coping strategy. However, this silence might also be related to the patients' poor physical condition, the acuteness of their situation when hospitalized, and feelings of being ignored.

The patients lived a cycle of intermittent exacerbations, 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 and understanding of the course and prognosis of COPD, as well as the rationale of using MV and NIV. They had no or very limited knowledge about any other treatment or care options that might ease their suffering. The patients were not

introduced to palliative treatment with oxygen and opioids, even though this treatment has showed robust evidence of effectiveness 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, although the usefulness of NIV treatment to relieve 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 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. This poor recollection may be due to the serious and acute nature of their situation. In these situations, the patients had a limited ability to partake in complex discussions and it is reasonable to believe that their decision-making capacity was reduced. However, none of the participants had engaged in a dialogue regarding their goals for their care, treatment, and prognosis, not even 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 should be prognosis, goals for treatment and care (MacPherson *et al.* 2013, Patel *et al.* 2012).

Studies have shown that patients with chronic illnesses considered their physician's involvement in their illness to be important for their trust in the healthcare system (Skirbekk *et al.* 2011). The relationship between patient and healthcare personnel is based on different roles. Patients are in need of help and care while the healthcare professionals are the ones who could be able to assist them. Such relationships are established through trust, and the paradox of trust is that trust itself cannot grow without first taking the risk of placing one's trust in others having first been taken (Carter 2009). The patients in this study experienced a lack of familiarity and interaction with both the nurses and the physicians.

COPD patients 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. They needed to believe that the healthcare personnel were willing to respond morally to their suffering and vulnerability, as in ACP.

When COPD patients are in remission, their gradual independence will lead to the possibility of making choices regarding trust. This situation renders each patient capable of choosing whether he/she wants to share his/her values and preferences regarding EOLC.

However, these issues are sensitive and highly emotive, so rather than putting themselves at risk of being rejected or ignored, patients might choose to remain silent. This attitude is reinforced by the healthcare system, on which they increasingly depend but which has failed to effectively advocate for their needs. This silence may weaken patients' autonomy, and consequently imply they will be met with a paternalistic attitude and excluded from participating in decision-making regarding 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 person's sense of deprivation regarding being able to share their thoughts, and it might increase their desire to receive comfort and care.

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. The findings from these interviews thus highlighted complementary aspects of the same phenomenon (Jerpseth *et al.* 2016a, Jerpseth *et al.* 2016b). In this way, we triangulated the depth of understanding of the data, thereby contributing to the overall goal of triangulating the likelihood findings (Creswell 2012). At the same time, the researchers' 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 patients with late-stage COPD competent care, it is essential that they understand how these patients' experience their illness. Our most striking finding was the patients' unmet need for care and communication regarding their grief and existential worries. Increasing awareness about the patients' challenges is important

in order to meet their need for comfort and care. Healthcare personnel have an obligation to ensure that patients are informed about the nature and prognosis of their disease, and to listen to patients' needs, values, and preferences. This requires the healthcare system to adapt so that the goal of disease management shifts from prolonging survival to palliative care, and so the need to include patients in decision-making processes can be accommodated. Advanced care planning and shared decision-making for patients with late stage COPD including discussion between patients and their care providers on how their condition may affect them in the future should be initiated.

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 explanation, it would be interesting to know if the health care personnel lack of moral responsibility was a failure of moral perception or lack of simple concern for patients' wellbeing or both. Being able to see what is at stake for the patient is a basic requirement of moral action and responsibility well recognized in moral theory (Blum 2009, Nortvedt 2016, Vetlesen 1994). Current concerns of bioethics include autonomy, the four principle approach, and respect for the patient's preferences. However, the failure to respect patients that we observed might also go deeper, showing a lack of receptivity, what I call moral perception. According to ethics of proximity and the French philosopher Emmanuel Lévinas, vulnerability and suffering exhibited in the human face is what awakens moral concerns and responsibility (Lévinas 1999). It is noteworthy that so apparent that the vulnerability that is so apparent in these patient stories is not recognized by the professionals. It will be important for future research to also investigate what causes such a failure of moral perception.

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Conflict of interest

The authors have no conflict of interest to declare.

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