

## **Considerations and values in decision making regarding mechanical ventilation for older patients with severe to very severe COPD.**

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## **Abstract**

*Background:* The different considerations involved in decisions regarding whether or not to initiate mechanical ventilation for patients with severe chronic obstructive pulmonary disease (COPD) are challenging for health professionals.

*Aim:* To investigate the considerations and values that influences decision-making regarding mechanical ventilation in older patients ( $\geq 65$ -years-old) with severe to very severe COPD.

Furthermore, it aims to elucidate how physicians involve their patient in decision-making process.

*Participants and setting:* Seven intensive care physicians and seven physicians working in the pulmonary wards at two university hospitals and two district hospitals in Norway.

*Methods:* A focus group study using a hermeneutic-phenomenological approach. The data was analysed according to the interpretative contexts: self-understanding, critical common-sense understanding and theoretical understanding.

*Results:* Decisions regarding mechanical ventilation were mainly based on the physicians' own experiences, their perceptions of the patients' situation, and biomedical data. The patients were not involved in the decision-making and such decisions were only occasionally made in a multi-professional context.

*Conclusion:* To decide whether older patients with severe COPD should be treated with mechanical ventilation is both medically and ethically challenging for physicians. Decision making in this context seems to be mainly driven by a paternalistic attitude, since the physicians interviewed in our study, in general, make such decisions without involving either the patient, their next of kin or the nurses. There is a need for broader cooperation between

health professional and for the involvement of patients in the decision-making process regarding mechanical ventilation in cases of advanced COPD.

**Keywords:** Professional Ethics in Medicine, Clinical Ethics, Codes of ethics, Aged and terminally ill, Health Care Quality, Quality and Value of Life.

## **Introduction**

Chronic obstructive pulmonary disease (COPD) is one of the fastest growing illnesses worldwide, as well as one of the major causes of death.<sup>1</sup> A wide range of burdens accompanies the advanced stages of COPD and even complete therapy often gives only modest relief of painful symptoms.<sup>2</sup> The trajectory of COPD is unpredictable and patients are frequently hospitalised. Although the average mortality rate following hospitalisation for acute exacerbation is falling, it still varies between 23%<sup>3</sup> and 80%.<sup>4</sup> Acute exacerbation in severely ill COPD patients often involves decisions about whether or not to initiate mechanical ventilation (MV). Such decisions are both medically and ethically challenging for the physicians and other health professionals involved, including nurses.<sup>5</sup>

Both Norwegian health policy guidelines and healthcare legislation have mandated the involvement of patients, their next of kin and a multi-disciplinary team in the decision-making process.<sup>6-8</sup> This corresponds with trends across the western world<sup>9-11</sup> and is likewise highlighted in the recommendations of the Global Initiative for Obstructive Pulmonary Disease (GOLD).<sup>1</sup>

Studies have shown that many physicians consider themselves to be the principal decision makers and so do not involve patients and other healthcare professionals in the decision-making process<sup>12-14</sup>. Such consideration on the part of physicians does not correspond with the national healthcare regulations or with research, that highlights how end-of-life (EOL) treatment planning should, if possible, be based on an agreement between patients, families and healthcare professionals so as to ensure the best quality of care corresponding to patients' values and preferences.<sup>9, 10, 15</sup> Several studies have shown that patients with severe COPD do not receive sufficient information about their diagnosis, prognosis and treatment options during the advanced stages of their illness. Additionally,

healthcare professionals are often unaware of their patients' values and preferences, and the patients themselves have only limited knowledge about their illness.<sup>11, 12</sup>

Studies have shown that physicians experience communication barriers when discussing the risk of admission to the intensive care unit (ICU), MV and poor prognosis with severely ill COPD patients, despite the recommendations that they do so.<sup>11, 16-19</sup> For example the American Thoracic Society, has recommended further research on palliative care and EOL discussions with patients, during the stable phases of COPD.<sup>20</sup> This paper therefore aims to investigate the considerations and values that affect the decision-making processes regarding MV in older patients ( $\geq 65$ -years-old)<sup>21</sup> with severe COPD. Furthermore, it aims to elucidate how physicians involve their patients in the decision-making process.

## **Methods**

The study follows a hermeneutic-phenomenological approach. Phenomenology contributes to the elucidation of sensibilities and thereby captures the immediate experience-based knowledge. Hermeneutics on the other hand, is the study of the interpretation of meaning, sought and attention to questions posed to a text.<sup>22</sup> In this paper, we aimed to identify the participants' subjective experiences of their considerations and values during the decision-making process concerning MV, and to interpret those experiences in order to gain a deeper understanding.

Focus groups are particularly useful for learning more about people's experiences in an environment where several persons interact, since the lively collective interaction may bring forth more spontaneous expressive and emotional views.<sup>22, 23</sup>

### ***Settings***

Two university hospitals and two district hospitals in the eastern and the western parts of Norway represented the field of research in this study. The four hospitals all provide advanced treatment for patients with COPD as well as general healthcare for a large section of the Norwegian population.

### ***Participants and recruitment***

The participants included seven (N=7) ICU physicians who were all anaesthesiologists and seven (N=7) physicians who were specialists in internal medicine on pulmonary wards (pulmonologists). In the decision-making process concerning MV, the ICU physicians and the pulmonologists all shared decision-making responsibility. Hence, it was of interest to capture both perspectives. Participant information is summarised in Tables 1 and 2.

In this study, the head physicians from the individual departments acted as gatekeepers during the recruitment process. They provided the names of physicians who might possibly be interested in participating. The first author then contacted the identified physicians by email. The email included information about the study and a consent form. None of the contacted physicians declined to participate.

TABLES 1 and 2

### ***Data collection***

The data collection process for this focus group study included four focus group interviews. We developed a semi-structured interview guide based on the research questions (Appendix 1). The interview guide was tested in a pilot interview prior to the original research. In that pilot interview, we discovered that the participants talked more freely about their experiences when they told stories about individual patients. Previous studies have demonstrated that physicians are happy to talk about ethically difficult situations, although they are usually unable to actually explain their ethical thinking. In order to investigate the moral feelings of

physicians, it is therefore better to ask them to relate stories about situations and actions they have actually participated in than to rely on a theoretical patient model.<sup>24</sup> We thus decided to allow the participants to begin with a discussion about a specific clinical situation they had recently experienced.

The focus group interviews were performed by one moderator (HJ) and one assistant (KH or PN). The participants in each focus group were invited to discuss a specific clinical situation regarding whether or not to initiate MV in patients with COPD, with a focus on the ethical considerations involved. The interview guide was used to steer the discussions in the focus groups towards answering the research questions. When necessary, follow-up questions were asked by the moderator.

The focus groups were held during spring 2013. All of the interviews were audiotaped and then transcribed verbatim by the first author. Field notes regarding participant interactions were added when appropriate.

## **Analysis**

We analysed the data according to Kvale and Brinkmann's three levels of interpretative analysis: (1) self-understanding, (2) critical common sense understanding, and (3) theoretical understanding.<sup>22</sup> In the context of self-understanding, the researcher seeks to render the individual perspectives of the interviewees. A critical common sense understanding involves an examination of the content of the interviews and raises critical questions regarding the textual transcripts. During this phase of analysis, we started to interpret the coded data. The main codes were split into sub-codes, spliced and linked together, and finally organised into main themes and subthemes. For our theoretical interpretation, the themes were reflected on according to the study's aims and the relevant literature. The ethical theoretical aspects were not decided on in advance. They appeared inductively through the analysis and interpretation.

In order to conceptualise and make visible the physicians' moral considerations, we found it illuminating to discuss the results in light of the ethical principles of beneficence, nonmaleficence, autonomy, and justice.<sup>25</sup> With the analysis, we tried to achieve a balance that captured the dynamic interplay between the individual and the group when reflecting on the questions posed.<sup>26</sup>

### *Ethics*

This study was conducted in accordance with the amended Declaration of Helsinki. Ethical approval for the study was obtained from the Regional Committees for Medical and Health Research Ethics (REC, South East Norway 12.04 2012/618C).

### **Results**

Overall, we found that the physicians faced several challenges during the decision-making process regarding MV. The results are organised into three main themes, with subthemes that complete and elaborate the findings as shown in Table 3.

Table 3

#### *Ambivalence and clinical uncertainty in an unpredictable chronic illness*

The ICU physicians and the pulmonologists in all of the focus groups agreed that the prognosis for severely ill patients with COPD is difficult to predict. The choice of whether to initiate, continue, or not provide MV was associated with varying degrees of ambivalence and uncertainty in the related decision-making.

Ambivalence was shown in the continual wondering about what was the right thing to do. As one physicians commented:

It is difficult to know whether the patient will benefit from MV treatment or if the treatment will instead prolong suffering and postpone death (ICU physician A, FG 4).

Ambivalence was also found to be connected to quality of life:

Often we do not know the patients. Do they have a low quality of life? However, what is a low quality of life? It is difficult.... (ICU physician A, FG3).

Uncertainty arises both because there is no clear point for patients with severe COPD at which curative care ends and palliative care begins, and because physicians have to base their decisions on their own perceptions of the likely course of COPD. In the quotations below, an ICU physician questions the lack of discussion regarding MV from the pulmonologists and a pulmonologist responds.

I wonder why the pulmonologists want to discussion about invasive MV for patients with severe COPD, but never for patients with advanced lung cancer.

The prognosis is about the same (ICU physician B, FG 3).

However, for patients with COPD it is difficult to know who will live for five years and who will die suddenly (Pulmonologist A, FG 3).

Several of the pulmonologists commented that, statistically patients with severe COPD have equally high mortality to the patients with lung cancer, but that they assess the challenges differently when it comes to communication regarding EOL treatment.

I always communicate with patients with lung cancer about death, but it feels unnatural to do the same with patients with COPD. They are too worried and we do not know the likely outcome. They might survive against all odds (Pulmonologists A FG 1).

I agree, the patients often know that they will die soon, without us telling them. I believe that it will do no good to speak about the fact that this disease will kill you (Pulmonologists B, FG 1).

Both the pulmonologists and the ICU physicians mentioned that uncertainty alone was frequently an argument for either initiating or continuing MV. When a patient with severe COPD is transferred to the ICU, it is problematic to end treatment that has already been started. Doubts about what is right or wrong seem to lead to intubation:

If in doubt, I intubate [...] whether I am right or not, [...] at least I have to treat (ICU physician B, FG 2).

### ***Barriers to systematic communication***

Neither the pulmonologists nor the ICU physicians reported having systematic routines for communicating with their patients about treatment options, prognosis, life expectancy, or end-of-life issues. Such communication was more complicated for the ICU physicians due to the acuteness of the situation when they first meet their patients. However, they described being only rarely informed of their patients' views on MV and cardiopulmonary resuscitation

(CPR). The following subtopics underline the barriers that contribute to the lack of communication with patients and their next of kin.

*Distrust and inconsistency in the patient's decision-making capacity*

Several of the physicians, both ICU physicians and pulmonologists, were doubtful about whether conversations regarding prognosis were in the best interests of their patients since patients rarely request such conversations. They claimed to doubt patients' ability to understand their own situation, and related this to what they suspected to be the patients' reduced intellectual and social capacities.

Some COPD patients do not know that they are dying from it. These patients are not exactly academics. There is no point in painting a darker picture. Perhaps they can live in ignorant bliss? (ICU physician A, FG 3).

Some of them know that they will die: they are heavy smokers and everybody knows that smoking will kill you. I have never received a question about death from a patient with severe COPD (Pulmonologist A, FG 3).

Some of the participants made it clear that, as physicians, they had to take full responsibility for all treatment decisions, since patient requests could appear inconstant and conflicting.

Patients sometimes say that they do not want to continue with treatment, but after treatment, they are thankful. Therefore, we cannot always take what the patients say at face value (Pulmonologist A, FG 3).

### *Shortcomings in communication*

The physicians reflected on their perceived shortcomings when they could no longer offer active treatment. The pulmonologists, in particular, experienced feelings of inadequate relational competence, while the ICU physicians blamed their perceived shortcomings more on lack of time. However, both the pulmonologists and the ICU physicians expressed how they rarely supported each other during difficult conversations with patients, and some described situations where they felt lonely and lacked someone to trust.

It is difficult and uncomfortable to tell patients that they are severely ill and might die from their illness. I feel like a poor physician, and I miss having a psychologist to break the news to the patient (Pulmonologist A FG 4).

It is difficult and unpleasant. As a physician, I have experienced that these conversations take time and I dread having to do so (ICU physician B FG 4).

### *Ambiguous communication with next of kin*

Both the ICU physicians and the pulmonologists shared different perceptions about the role of the next of kin in decision-making. They found some next of kin to be helpful, but others to be demanding. One physician explained:

I ask the next of kin what they think their mother wants, and in that way we reach a decision (ICU physician A, FG 1).

In one focus group, the physicians described the difficulty they experience when the next of kin demand continuation of treatment despite the fact that the patient is suffering. The

participants described feeling powerless when confronted with unrealistic expectations on the part of the next of kin. Nevertheless, they did more or less, as was demanded of them.

Many next of kin are extremely pushy. [...] However, I have started to give up a little (Pulmonologist B, FG 4).

On the other hand, other participants, in particular the ICU physicians said that they missed the presence of a next of kin for some of their patients who did not have anyone to stand up for them.

Many of our patients in this hospital are lonely. They do not have any next of kin who is competent, to provide the information (ICU physician A, FG 3).

*Organisational barriers to involving patients in decision -making*

In particular, the ICU physicians referred to the system at the hospital, which did not secure continuity throughout the patients' hospital stay. A lack of continuity rather than a lack of time could be a barrier to good communication. Additionally, acute situations require rapid action and do not allow room for information seeking and conversations. As one physician remarked.

We cannot gather all kinds of information when the patient is half dying (ICU physician A, FG 2).

One of the pulmonologists said:

I do not ask the patient what treatment they want the next time they become similarly ill, but I do tell some patients that they will not receive the same intensive treatment again, and then I write that in their medical record (Pulmonologist B, FG 1).

The participants highlighted a problem in the fact that, often, it is the least experienced physicians who first meet the patient in an acute situation. This was expressed as a factor that could lead to both under- and overtreatment, along with incomplete recording of relevant information in the patient's medical record regarding their functional status and quality of life. Thus, physiological outcomes such as lung function or functional capacity were crucial for deciding the intensity of treatment.

The pH value and previous MV treatment often decides. If the patient has never been treated on a ventilator, then you have to try it (ICU physician B, FG 2).

#### ***Insufficient interdisciplinary collaboration***

The interdisciplinary cooperation between ICU physicians, pulmonologists, and nurses depended on the workplace culture, personal attitudes, and the roles and perspectives of the different professionals. Both the ICU physicians and the pulmonologists considered themselves autonomous in making medical decisions. Generally, the nurses who were caring for the patients were not involved in the decision-making process.

Sometimes we discuss the matter with the nurses, but often we take the decision among our 'own' profession. The nurses have to act according to our decisions. They are within their rights to speak out their opinions. Nevertheless, it is our responsibility to decide (ICU physician A, FG 3).

However, one ICU physician stated that he always conferred with nurses, arguing, "they know the patient best" (ICU physician A FG1).

### *Differences in perspectives and roles*

The pulmonologists and the ICU physicians described their collaboration as uncomplicated, although characterised by a lack of communication. Some of the ICU physicians perceived the pulmonologists to be over-optimistic in their assessment of treatment benefits of MV in cases of severe COPD. The ICU physicians acknowledged that they do not know the patients in the same way as the pulmonologists, but still considered it to be their role to act as the gatekeeper to more advanced treatment, in the ICU.

I often consider the situation differently than the pulmonologist. I have to think about the consequences of giving MV. Will this patient manage to recover and be able to breathe without ventilation support? The treatment on MV is burdensome and we have to consider whether the patient will profit from the treatment or whether this intensive care only will prolong the dying process? (ICU physician A, FG 4).

### *Tension between ICU physicians and pulmonologists*

None of the participants felt that there were conflicts among the ICU physicians and the pulmonologists, instead reporting interactions of the kind that one pulmonologists described as “fruitful discussions”. However, the discussion below elucidates some tension and disagreement in questions of treatment:

When I see these COPD patients who come in for the sixteenth or seventeenth time, their faces blue and completely exhausted. I think, why have they not been allowed to die sooner? We never stop - it is undignified. I have worked in other hospitals in Norway, and in this hospital, I feel that we treat COPD patients more intensively (ICU physician B, FG3).

I think the patients who are treated in this hospital are lucky (Pulmonologist A, FG 3).

Maybe! I am not sure that I agree (ICU physician B, FG 3)

## **Discussion**

Overall, our findings indicate that the decision-making process regarding MV for severe COPD patients is both medically and ethically complex, and that the decisions made are highly value-based. The results are discussed in the light of the four medical ethical principles identified by Beauchamp and Childress: beneficence, nonmaleficence, autonomy and justice.<sup>23</sup> These principles are not exhaustive. They do, however, provide a fruitful characterisation of the central ethical concerns in medicine.<sup>23</sup> In a clinical setting, where physicians meet individual patients, these principles may conflict with each other, as seen in our study.

### *Tension between nonmaleficence and beneficence*

The principle of nonmaleficence means to not to inflict harm on others and has been closely associated with the maxim “above all do no harm”. There is no clearly defined distinction, however, between not inflicting harm and providing benefit. Rather, these two outcomes are to be understood as being on a continuum of morally relevant considerations.<sup>25</sup> Historically, physicians have relied almost exclusively on their own judgement regarding what was best for their patients, without respecting patient self-determination.<sup>27</sup>

The physicians in this study reported facing the following challenges: the unpredictable course of the disease, the fact that patients are in acute need of help, and the assumption that information can cause harm to patients.

The participants also maintained that it is inappropriate to stop and gather information about patients' preferences and values when they are struggling to breathe. The physicians experienced their patients' struggles as a professional demand for action. However, they found no time to communicate with the patients once they were stabilised. Their main concern was to do what they believed to be best for their patients, paradoxically without knowing what the patients themselves valued. Decisions regarding treatment seemed to be based on objective medical criteria such as the pCO<sub>2</sub> and FEV<sub>1</sub> as well as the individual physician's personal judgment and preferences, whereas the patient's own preferences and experiences seemed to play only a minor role. However, objective criteria such as the FEV<sub>1</sub> have shown poor correlation with patients' perceptions of their life quality and symptoms.<sup>28</sup> If physicians believe that information about quality of life is important, they should ask the patient. However, this is not something the physicians in our study generally do. If they believe that quality of life assessment is problematic, that is another issue. Yet it is impossible to argue that without first asking the patient. Studies have shown that physicians consistently underestimate their patients' quality of life as compared to the patients' own assessments, and this may be a reason for under treatment.<sup>29-31</sup> Recent recommendations emphasise the use of consideration of patient-centred outcomes, as well as physiological and functional capacity, in reaching decisions regarding treatment.<sup>20</sup>

The physicians in this study claimed that it is almost impossible to provide patients with information about their prognosis because of the unpredictable trajectory of their condition. This absence of communication is often described as "prognostic paralysis" where the clinicians responsible for patients with uncertain illness trajectories prevaricate concerning EOL issues.<sup>32</sup> However, the unpredictable illness trajectory should not preclude such a discussion.

In our interviews, the physicians asked for guidelines for the decision-making process. Both national and international guidelines do exist for treatment and decisions regarding EOL issues,<sup>5,7,8</sup> although these guidelines seem to have been poorly incorporated in Norwegian hospitals. Strong paternalism is also evident in the failure to share information with competent patients and the similar failure to include them in decision-making about their own future and wellbeing. It is the clinicians' responsibility to be aware of relevant legislation and to ensure that patients are included in decisions about their treatment and care.<sup>7</sup>

### *Respect for patient autonomy*

In medical ethics, respect for the patient autonomy for competent patients is regarded as a universal and absolute moral principle.<sup>25</sup> Some of the participants in our study suggested that "not knowing" was in the best interest of patients with severe COPD. However, the idea that not revealing a poor prognosis spares patients unnecessary suffering is contradicted by studies showing that most of the patients want to take part in decisions concerning their own treatment and care and how they might die. They want their doctors to raise these questions in a trusting and communicative atmosphere.<sup>33, 34, 35, 36-39</sup> Ensuring that patient who wish to discuss EOL care have the opportunity to do so, will improve the outcomes for both patients and their families. This conversation should include discussion concerning the goals of 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.<sup>40, 41</sup> Advanced care planning (ACP) is one way to initiate these conversations with patients and so to improve their quality of life, during the very severe stages of the illness.<sup>42, 43</sup>

While the physicians interviewed in this study considered their patients' statements about further treatment to be unreliable, inconsistent, and thus not fully autonomous decisions, previous studies have suggested that older patients' preferences concerning

treatment intensity are indeed stable over time.<sup>44-46</sup> However, one study showed that one-third of outpatients with severe organ failure changed their preferences regarding CPR or mechanical ventilation at least once during the one-year follow-up period.<sup>47</sup> These findings suggest that physicians have to communicate frequently with their patients in order to properly assess patient competency in each individual case.

There might be several reasons why physicians would consider their own autonomy as decision makers to be more important than respect for their patients' autonomy. Physicians might experience a social and/or intellectual distance between themselves and patients with COPD, which could lead to difficulty in establishing a trusting relationship. Elderly patients with COPD seldom express their desires for information and involvement in decision making about their treatment.<sup>48</sup> Their silence might be interpreted as a lack of desire to discuss their prognosis, treatment, and goals with their physician. Together with the physician's own shortcomings in terms of initiating difficult conversations, the misinterpretation of a patient's silence about his/her information needs may deny the patient the opportunity to communicate their own preferences, thus leaving complicated decisions to their next of kin. Additionally, nurses, who often know patients well, rarely take part in treatment decisions, which may lead to a further weakening of the patient's voice in decision-making.

#### *Challenging the principle of justice*

Justice is a core value in the ethics of prioritisation in the Norwegian health service.<sup>6</sup> Limited information from the patients themselves appears to strengthen the voice of the next of kin in decisions about treatment in situations where the patient lacks the capacity to make decisions. However, the role of the next of kin as a source of information and a spokesperson for the patient's best interests might be problematic. The next of kin may be tired and stressed and therefore incapable of understanding the complexity and seriousness of the situation. They

may not know the patient's preferences and they often need considerable care and information themselves.<sup>41, 49, 50</sup> Our findings highlight how the physicians experienced a considerable difference between cases where patients have a resourceful and demanding next of kin and those where patients do not have anyone. Even though the physicians defined themselves as the autonomous decision makers, they do listen to the demands of the next of kin. Some of the physicians even said that they had given up, and simply do as the next of kin demands. From this perspective, the most vulnerable patients, those who are alone, might be given lower priority in both care and treatment. This finding presents a challenge to the fair and equal treatment of patients.

The different perspectives and values of the ICU physicians and the pulmonologists, both between and within their professions, may also jeopardise fair treatment and care. A practice more in line with the available guidelines may be helpful in securing justice in treatment practice.<sup>50</sup>

### *Methodological considerations*

In focus group studies, it can be challenging to preserve individual experiences in a group context. To address this challenge, we arranged small groups in which all the participants had a common professional background, and we ensured that everyone had the opportunity to speak. This study is qualitative and descriptive, and so the possibility for generalising is limited. However, the findings provide insight that has transfer value to healthcare providers who care for patients with severe COPD and other severe to very severe chronic illnesses, such as renal failure and heart failure in older patients.

## **Conclusion**

Decision-making concerning whether or not older patients (>65 years) with severe to very severe COPD should be treated with MV is medically and ethically challenging for physicians. Patient involvement in decisions about their treatment and care during the severe stages of the illness is rare. Instead decision-making seems to be more influenced by a paternalistic attitude whereby physicians consider their own autonomy as decision makers to be more important than respect for patient autonomy.

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