



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

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Abstract

Background: Decisions regarding whether or not to institute mechanical ventilation during the later stages of chronic obstructive pulmonary disease is challenging both ethically, emotionally and medically. Caring for these patients is a multifaceted process where nurses play a crucial role.

Research question and design: We have investigated how nurses experienced their own role in decision-making processes regarding mechanical ventilation in later stages of chronic obstructive pulmonary disease and how they consider the patients' role in these processes. We applied a qualitative approach, with six focus-group interviews of nurses ($n = 26$).

Ethical considerations: The Regional Committees for Medical and Health Research Ethics approved the study. Voluntary informed consent was obtained.

Findings: The nurses found themselves operating within a cure-directed treatment culture wherein they were unable to stand up for the caring values. They perceived their roles and responsibilities in decision-making processes regarding mechanical ventilation to patients as unclear and unsatisfactory. They also experienced inadequate interdisciplinary cooperation.

Discussion: Lack of communication skills, the traditional hierarchical hospital culture together with operating in a medical-orientated treatment culture where caring values is rated as less important might explain the nurses' absence in participation in the decision about mechanical ventilation.

Conclusion: To be able to advocate for the patients' and their own right to be included in decision-making processes, nurses need an awareness of their own responsibilities. This requires personal courage, leadership who are capable of organising common interpersonal meetings and willingness on the part of the physicians to include and value the nurses' participation in decision-making processes.

Keywords

Chronic obstructive pulmonary disease, end-of-life decision-making, mechanical ventilation, nursing ethics, caring values

‘Sometimes, I feel like an angel of death’

Introduction

Patients with severe to very severe chronic obstructive pulmonary disease (COPD) experience an extremely challenging illness, which causes them to become fragile and vulnerable. They often suffer from a wide range of problems, including breathlessness, pain, malnutrition, sleeplessness, anxiety and a fear of dying. During the later stages of COPD, the illness has an unpredictable trajectory,¹ where acute exacerbations are associated with increased morbidity and mortality, high readmission rates and a high risk of mechanical ventilation (MV).² Although the prognosis is about the same for COPD as it is for lung cancer, COPD patients rarely received planned end-of-life care (EOLC).^{3–5} Caring for these patients is a multifaceted process where nurses play a crucial role.

Limiting intensive treatment for patients with a serious deterioration of COPD is closely associated with end-of-life (EOL) decision-making and EOLC. In this study, we defined EOLC as care intended ‘to assist persons who are facing imminent or distant death to have best quality of life possible till the end of their life regardless of their medical diagnosis, health conditions, or age’.⁶ Decisions about MV during the severest stages of COPD are challenging both ethically and emotionally as well as medically. The need for MV mainly arises during the phase of the illness in which fear of imminent death and dying may be prominent and hence may cause great emotional strain for the patient, their family and the healthcare professionals.

Norwegian healthcare legislation and the International Council of Nurses’ codex, as well as various international and national guidelines, all underline the need for EOL decisions to stem from a collaborative agreement between qualified personnel and patients and/or their families.^{7,8} However, studies show that healthcare professionals rarely engage in dialogue with patients suffering from severe COPD regarding their treatment options and care possibilities when the illness worsens and enters a more terminal phase.⁹ This is contrary to research showing that most of the patients want to participate in decision-making about their EOLC.^{10–12}

EOLC represents an important part of the nurses’ professional responsibilities when it comes to caring for patients with severe COPD, and research describes the importance of nurses’ role in EOL decision-making.^{13–15} Nurses are arguably the healthcare professionals who spend the most time with patients and their families. Empathy and moral sensitivity towards the patients’ suffering, as well as understanding the patients’ subjective experiences of the illness, are crucial values in nursing.¹⁶ Based on such values, nurses often grow to know the patients well and so can address questions about the patients’ values and preferences in a sensitive way without causing too much distress.^{17–19} The nurses often hold a key position in coordinating the overall care for the COPD patients, and might be the first to observe changes in the patients’ condition as well as the eventual need for EOLC. Research also shows that giving nurses more responsibilities in EOLC presents an effective use of healthcare resources with regard to these patients.²⁰ Despite this, studies have shown that nurses are rarely involved in the clinical and ethical decision-making processes regarding EOLC.^{17,18,21,22}

To our knowledge, there has been only limited research on how nurses enact their roles in EOL decision-making processes regarding severely ill COPD patients. The aim of this study was, therefore, to elucidate

how nurses experience their own role and care in these decision-making processes. Furthermore, the research aims to elaborate how nurses perceive the patients' role in the decision-making process.

Methods

Design

This study has a qualitative design, where the data collection method consisted of focus-group interviews with nurses. The investigation forms part of a larger project consisting of two other sub-studies: (1) focus-group interviews with intensive care unit (ICU) physicians and respiratory physicians and (2) in-depth individual interviews with patients suffering from very severe COPD.

Focus-group interviews are particularly suitable when the aim is to learn more about individuals' experiences, as well as their viewpoints and attitudes in decision-making processes. Focus groups are useful for exploring and discussing 'what', 'how' and 'why' the nurses think as they do when interacting with COPD patients. These interviews capitalise on group dynamics and cultural understandings, and thereby one can obtain information that may not be available through individual interviews.²³

Settings, recruitment and participants

The fieldwork of this study was done in two university hospitals and three district hospitals in eastern and western regions of Norway. All the five hospitals provide advanced treatment and care for patients with COPD as well as general healthcare for a broad section of the Norwegian population. Five senior nursing officers recruited nurses from the hospitals' ICU ($n = 12$) and from the respiratory unit (RU) ($n = 14$). The senior nursing officers provided the names of nurses who might be interested in participating. The first author (H.J.) then contacted the nurses by email. The email included information about the study and a consent form. All of the invited nurses agreed to participate in the study.

The participants in each focus group came from the same hospital. As can be seen from the composition of the six focus groups (Table 2), there was one group with only nurses from ICU and another group with only nurses from the RU. Due to the heavy workload in the ICU on the day the interview was scheduled, we had to split the focus group. We considered such a splitting of the group as acceptable, since we found that the data were sufficiently saturated after the first four focus groups. Nonetheless, we decided to conduct the final two groups in order to determine whether a group consisting of only nurses from RU or ICU allowed the discussion to deepen and/or encouraged new knowledge to appear.²⁴

The information regarding participants is summarised in Tables 1 and 2.

Data collection

A nurse and a respiratory physician tested the interview guide prior to the original research. Based on their feedback, we revised the questions so that they were more open-ended. Additionally, we decided to interview the physicians and the nurses in separate focus groups in order to avoid a situation where the nurses and the physicians were restricted in their openness towards each other.

One moderator (H.J.) and one assistant (K.H. or P.N.) conducted the six focus-group interviews between December 2012 and April 2013, at a rate of one to two interviews per month. The interviews had an average duration of 65 min.

All of the focus groups began with an invitation to describe and discuss a specific clinical situation in which the participants had to make a decision regarding initiating, continuing or discounting MV. This

Table 1. Demographic data of the participants.

	Nurses in ICU wards	Nurses in RU
Men (n = 2)	0	2
Women (n = 24)	12	12
Age, M (min–max)	38 (31–55)	34 (25–47)
Experience in ICU/RU (years) (min–max)	8 (1–14 years)	6 (9 months–15 years)

ICU: intensive care unit; RU: respiratory unit.

Table 2. Composition of the focus groups.

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

ICU: intensive care unit; RU: respiratory unit.

open-ended invitation ensured that the participants shared both opinions and experiences. In addition, the same semi-structured interview guide was used in all of the interviews.

The interviews were audio-taped and then transcribed verbatim after each interview by H.J. Field notes regarding participants' interactions were added when appropriate.

Analysis. The data were analysed according to Kvale and Brinkmann's three levels of interpretative analysis: (1) self-understanding, (2) critical common sense understanding and (3) theoretical understanding.²³ In the context of self-understanding, the researcher seeks to capture the individual perspectives of the interviewees. The context of self-understanding interpretation starts already during the interviews by asking the informants whether we have understood their expressions correctly. Furthermore, listening to, transcribing and the first naive reading of the transcripts, as well as starting to code meaningful units in the data, were important in capturing the perspectives of the informants. Critical common sense understanding involves an examination of the content of the interviews and raises critical questions about the textual transcripts. During this phase of the analysis, we continued coding and started to interpret the coded data. The main codes were split into sub-codes, then spliced and linked together, and finally organised into main themes and subthemes. The theoretical understanding stemmed from relevant research, ethical theory and principles as well as guidelines and regulations.^{7,25,26}

Ethical considerations

The Regional Committees for Medical and Health Research Ethics (REC) approved this study (ref 2012/618). All participants gave their written, voluntary consent. The participants were informed about their right to withdraw from the study at any time of the research process.

Results

Overall, we experienced these findings as serious and discouraging in terms of EOLC for patients with COPD. The nurses described the patients' appeals for help due to pain, breathlessness, anxiety and an unmet need to communicate regarding their EOL. There were several reasons why the nurses largely failed to act on the patients' needs concerning EOLC. The first main theme relates to how the nurses often experienced having to act against their caring values, such as to relieve suffering, provide comfort and safety, protect

Table 3. Themes identified within the results.

Main themes	Sub-themes
Acting against caring values	<i>Unable to provide EOLC</i> <i>Prolonging suffering rather than protecting from harm</i> <i>Concerns about overtreatment</i> <i>Feeling like an ‘angel of death’</i>
Unclear role and professional responsibility in patient communication regarding MV	<i>Physicians’ task to communicate</i> <i>The dilemma of acuteness</i> <i>Unclear and vague role in decision-making process</i> <i>Not being part of interdisciplinary discussions</i>
Inadequate interdisciplinary decision-making processes Experiences of patients’ autonomy in the decision-making concerning MV	<i>Negligible role in interdisciplinary decision-making</i> <i>Disregarding patients’ autonomy</i>

EOLC: end-of-life care; MV: mechanical ventilation.

from harm and provide care, when treating severely ill COPD patients. The second main theme addresses nurses’ vague and unclear professional role in the decision-making process, while the third theme focuses on the nurses’ experience of an absence of interdisciplinary teamwork. Moreover, patient autonomy was not taken into account in decision-making regarding MV, which is elaborated in the fourth main theme. The main themes are shown in Table 3.

Acting against caring values

The nurses told stories about very vulnerable patients experiencing severe suffering, about patients who had been in and out of hospital in between 10 and 25 times over the last year and on and off MV. Patients conveyed that they no longer believed they had any quality of life, and many were lonely and scared of dying. They struggled with breathing and had prior to exacerbation, a lung-function that left them hardly able to move about in their own homes. Most of them suffered from undernourishment and cachexia. They were in constant pain and were very weak. These patients were in great need of care, trust and comfort. The nurses described the dilemma of being part of a medical treatment culture rather than being able to focus on the patients’ need for good care at the EOL. This medical culture was said to be focused on patients’ capacity to breathe, and so, the only solution offered to patients was either non-invasive ventilation (NIV) or invasive ventilation. It was obvious that these patients needed ventilation assistance, but at this stage, the patients’ situation was so complex that the nurses felt they needed care that extended beyond simply treatment with NIV or MV. The nurses experienced a lack of authority to act; however, they felt that they should have acted on the caring needs of the patients. Indeed, they felt like they acted against their caring values.

Unable to provide EOLC. All of the nurses experienced that patients with severe and terminal COPD often received aggressive treatment until death rather than EOLC. Several of the nurses expressed concerns about the lack of systematic and appropriate care for these patients compared to patients with cancer diagnoses. They all felt that they were giving futile and undignified treatment:

Even though the course of COPD is difficult to predict, we do know that the sufferers are seriously ill and that they are dying from the disease. Compared to patients with cancer, these patients do not get any communication about EOL or any planned palliative care. (Nurse 1, RU, FG 5)

Prolonging suffering rather than protect from harm. The nurses stated that their primary focus and professional goals were to prevent the patient from suffering. They perceived patients with severe COPD to be vulnerable and troubled by pain and anxiety. They often felt that the use of MV during the severest stage of the disease implied an obvious risk of prolonged harm, rather than being beneficial for the patient:

We observe all the suffering to a much greater extent than the physicians do, and that is what makes it so hard to be a nurse. Sometimes the patient is allowed to die, but not often. The technology keeps them alive, but what kind of life is it? Nobody asks. (Nurse 2, RU, FG 4)

Concerns about overtreatment. All of the participants expressed concerns about participating in overtreatment as well as prolonged treatments with poor outcomes. Implementing the physicians' decision in these cases caused an ethical dilemma because in the nurses' opinion, the physicians focused on life-preserving treatment, which extended suffering, while the nurses paid more attention to protecting the patients from harm:

The doctors belong to a tradition where it is the treatment that is extremely important. They want to cure. They do not want to 'give up' and so they keep on treating patients even though they must realise that the treatment is futile. (Nurse 2, ICU, FG 2)

I believe that the physicians are afraid of not doing enough [...], afraid of criticism, and therefore continue aggressive treatment, regardless of the consequences for the patients. (Nurse 2, RU, FG 2)

Feeling like an 'angel of death'. Raising questions about futility, overtreatment and prolonged suffering was difficult for the nurses. They felt that physicians perceived these questions as either nagging or wanting the patient to die:

I think it is terrible to nag. I observe all the suffering, all the needles, the pressure sore due to the ventilation mask, and the patients' anxiety. This futile treatment is in my opinion a kind of medical rape. I ask the physicians: when should this suffering end? In asking these questions repeatedly, I sometimes feel like an 'angel of death'. (Nurse 1, PW, RU 4)

Unclear roles and professional responsibility in patient communication regarding MV

One important reason for not being able to act upon the nurses' caring values and what they believe to be in the best interests of the patient was related to the unclear professional roles and responsibilities in both the decision-making process and care regarding severely ill COPD patients.

Physicians' task to communicate. Although the nurses spent much time with the patients and had possibilities to communicate with the patients about their preferences regarding MV at this serious stage of their illness, they hardly ever did. The nurses felt that this was not within their professional jurisdiction. Most of them claimed that communication regarding treatment and care options was primarily the responsibility of the physicians:

It [talking about instituting MV or not] is the physicians' task. We are not responsible for the communication with the patient about what happens the next time he experiences a serious exacerbation. (Nurse 2, RU, FG 3)

The dilemma of acuteness. The unpredictable disease trajectory of COPD, and the fact that the patients were often in an acute need of medical help when they were hospitalised, was emphasised by the nurses as factors

that complicated communication with patients. None of the nurses said that their units had routines in place regarding communication with patients about what the severest stage of the illness could be like. There was also no routine in place for examination of the patients' values and preferences about their treatment and care:

Many [physicians and nurses] experienced that it is wrong to initiate the conversations about the patients' preferences regarding their treatment, because they are in such a bad state, and it is a kind of chaotic situation. Maybe this apprehension is wrong, because I think most of the patients do think about death, but we still resist communicating about this matter. (Nurse 1, ICU, FG 6)

It is difficult to know when the time [for conversation] is right because sometimes the patients do get better against all odds. (Nurse 2, ICU, FG 6)

Nurses in the RU often talk to patients before they are discharged from hospital about their care needs. Nevertheless, they did not regularly communicate with patient about their preferences regarding MV or other treatment options as forms of palliation and care that might ease their suffering:

We do not communicate with patients about these matters [MV, EOLC] when they are discharged from the hospital. (Nurse 2, RU, FG 3)

Some of the nurses expressed that although they did not have any formal decision-making authority, they believed that it would be advantageous for the patients that nurses were present at discussions about treatment and care options. From the bedside, they had often heard patients expressing their concerns and values, and so followed their suffering closely. Nevertheless, the nurses did not play any clear and respected role in interdisciplinary discussions regarding what would be the right treatment during the severe stages of COPD.

Inadequate interdisciplinary decision-making processes

Under this main theme, the focus is on the nurses' role in interdisciplinary decision-making processes. In addition, we will elaborate how the nurses' absence in interdisciplinary teamwork has negative consequences for the severely ill COPD patients.

Negligible role in interdisciplinary decision-making. All of the nurses claimed that they were seldom invited or included in discussions about treatment options related to decision-making. This exclusion from important discussions made them unsure of what to say to the patients about their care and treatment:

We [the nurses] are in a very stressful situation due to the uncertainty about the treatment level. We do not know what to do, and it is impossible to communicate with the patients when their conditions are worsened due to an exacerbation. A few doctors will discuss this with us, mostly those with many years of experience, but there are not many. When that happens, I am happy. (Nurse 1, RU, FG 3)

The nurses expressed appreciation for the few physicians who did include them in the decision-making processes and who were interested in their opinions. The nurses gave different answers regarding their experiences of the inadequacy of interdisciplinary collaboration between physicians and nurses. Some voiced the fact that the physicians spent only minimal time on the wards and that they were too busy to start a conversation. Several of the nurses experienced that the physicians did not regard their observations about a patient's changing condition as important in either clinical or ethical considerations. The interdisciplinary conversations that did take place were short and primarily involved information about the

patients' objective symptoms directly related to their lungs and laboratory tests. In these short meetings, there was no room to discuss the patients' participation in treatment and care planning, or pay attention to the patients' subjective suffering, functional status and quality of life:

The dream is that the nurses and the doctors talked together, and discussed patients' goals for their care and treatment. However, it does not actually happen. (Nurse 3, ICU, FG 2)

The nurses experienced that there were often disagreements between respiratory physicians and ICU physicians and they felt that both the decision-making process and the patients' suffering were prolonged due to such disagreements between medical specialists:

Sometimes we do not know the intensity of treatment. There is a kind of battle going on between the anaesthesiologists and the pulmonologists, and we have to wait and see what decision they agree on. (Nurse 1, RU, FG 1)

Patients' autonomy in the decision-making concerning MV

Not knowing what the patients really wanted in terms of MV was an ongoing dilemma faced by ICU nurses as well as those from the RU. They experienced that even when the patients' preferences were known, in many cases their autonomy was disregarded.

Communication with the patients regarding their opinions and thoughts about MV was not structured, planned or systematised. None of the nurses considered this conversation to be one of their responsibilities. In response to a question from the moderator about the nurses' reasons for not communicating with patients regarding their values and preferences, some of the nurses claimed that it was difficult to find the time and appropriate circumstance for such a conversation. Moreover, as elucidated in the second main theme, the nurses felt that they had no clear role in communication with the patients:

It is an ethical dilemma whether we treat the patient with MV and do so without knowing what the patient really wants. (Nurse 2, ICU, FG 2)

The typical scenario is that the patient has been treated with MV many times, but we all know that one day, such treatment will not be enough. However, nobody discusses this matter with the patient. (Nurse 2, RU, FG 2)

Disregarding patients' autonomy. All of the nurses noted some disregarding of the patient's autonomy. They reported frustration with this situation, since it represented a violation of the patient's own will and decision-making capacity. The nurses related situations where the patients could initiate a conversation regarding their preferences for MV treatment. However, in many cases, these preferences were ignored and not documented in the patient's medical record:

I have participated in intubating patients who clearly expressed that they did not want to undergo MV. Nevertheless, the physician said that it must be done [...]. Discussions about MV have no value when the patient's condition has deteriorated. In that phase, the patients are not considered as competent to consent to the level of treatment anymore. (Nurse 2, ICU, FG 2)

Questions about whether or not to institute MV mainly arose when the individual patient's condition deteriorated. Making a decision to withholding MV at this stage was complicated. Nevertheless, the nurses sometimes felt that the patients' autonomy was disregarded. In some cases where a patient had clearly stated what he/she wanted, and where the nurses and the patients had tried to convey the message, the treating physicians would not listen. Indeed, as one of the nurses put it, the only way to get a physician to listen is 'to tattoo the message on the tongue; no tube' (Nurse 2, ICU, FG 2).

Discussion

The results from this study indicated that the nurses generally perceived their role and responsibilities with regard to severe COPD patients to be unclear. There might be several reasons why the nurses experienced a feeling of diminished responsibility. The nurses may feel that they lack the knowledge and skills necessary for effective EOL communication, which might lead to various distancing tactics so as to not get too involved with the patients.²⁷ However, our findings are in accordance with research showing that rather than lacking communication skills, the nurses did not consider themselves sufficiently experienced to participate in decision-making regarding sensitive matters.^{17,18,28} This is contrary to research highlighting how nurses may play a significant role in EOL communication.²⁹ Yet, in this study, the nurses are specialists and the patients suffer from cancer, which, unlike COPD, has an established strategy for EOLC.³⁻⁵

Another reason for the nurses' role might be that the hierarchical hospital culture fosters the maintenance of traditional roles for doctors and nurses, which might explain why the nurses did not consider themselves sufficiently experienced to participate in decision-making. In such a hierarchical environment, the nurses might see themselves as subordinate to the physicians. They might not realise their personal responsibility in terms of care and communication with patients about their preferences regarding medical treatment with the patients independent of the physicians.³⁰ To remedy this experience of not being included in decision-making, the findings show that the nurses used indirect techniques to influence the physicians' decision. This subtle action, presented in this study as feeling like 'nagging for care', illustrated the nurses striving to play a part in the decision-making processes, while still not having any formal decision-making authority. The dynamic in the decision-making process is often reinforced by the physicians' behaviour, because according to the nurses, they generally perceive themselves to be the sovereign decision makers. Such a culture is contrary to legal requirements, and even more significantly, it threatens patients' autonomy and their patients' right to qualified care.^{7,8,31,32} If a voice so close to the patients as that of the nurse treating them is not heard, then medical decision meant to be in the best interests of the patient will be uninformed and suboptimal. The responsibility for ending this hierarchical hospital culture does in part lie with the nurses themselves, although the physicians have the primary responsibility for facilitating a democratic and patient-centred culture as they have the final say in questions about medical treatment. The organisation of the cooperation as well as leadership will also play a central part in changing this culture.

The nurses described as operating in a medical-orientated treatment culture rather than in a culture that focused on care. Prognostic uncertainty and the availability of life-sustaining technology seem to enforce a moral imperative to use the technology. However, there are aspects of the culture of medical treatment that seems to obscure communication and holistic perspectives on patient care during the severest stages of COPD. The focus on medical treatment within a technology-oriented culture might distance nurses from their ability to engage in meaningful dialogue and ask insightful questions about the patients' values and preferences regarding MV.

Nurses have a unique perspective that allows them to be aware of when a patient is not responding to treatment.³³ Several of the nurses in this study reported their experiences of moral dilemmas related to the worsening of a patient's situation and simultaneous feelings of powerlessness and an inability to reduce the patient's suffering due to poor communication with physicians. Specifically, such moral dilemmas arise when the nurses have to implement a plan for treatment that contradicts their nursing values and their informed understanding of the patient's situation. These experiences could result in psychological burnout and moral distress. Additionally, they could lead to reduced patient autonomy and suboptimal treatment. Moral distress occurs when practitioners feel certain about the ethical course of action, yet are unable to follow their convictions.³⁴ In this study, the nurses expressed their moral distress about aggressive treatments that they considered to be futile and to prolong patients' suffering.

Nurses' traditional dependence and loyalty to physicians have been controversial for nurses whose chief commitment is to their patients.³⁵ Getting to know the patient is essential to nursing and is a mark of nurses'

expertise.³⁶ However, nurses seem to have to juggle multiple loyalties in healthcare systems, and such conflicting loyalties have left them struggling to reconcile their own values and the values of others.³⁷ These split feelings relate to their sense of responsibility, both to the patients and to following the physicians' professional options about treatment. In this study, striking a balance between these two responsibilities was said to pose an ethical challenge, which sometimes caused a feeling of powerlessness and of having to act against nursing values. In this sense, professional collaboration is both a precondition and an outcome of nurses' autonomy.³⁸

This study highlighted that the nurses were nearly absent from the EOL decision-making processes. This absence may lead to a lack of the important nursing perspective in clinical decision-making and caring for the patient. Patients with severe COPD are entirely dependent on the healthcare personnel. Regarding this asymmetry in authority relation, nurses should be especially aware of their responsibility to be involved in decision-making if the patients want it to be so. The nurses in this study related their concerns regarding patients' suffering. They described patients who received MV support and expressed distress over this intervention towards their EOL, but who were rarely invited to discuss their treatment and care options with either physicians or nurses. However, none of the nurses had any suggestions about how they could better include patients in EOL decision-making processes instead some of them argued for shifting the responsibility over to the physicians. To ensure well-planned care based on the needs of patients, systematic communication about their values and preferences is particularly important. The absence of this conversation reduces patient safety and the possibility for good patient care while each patient's autonomy is also weakened. By contrast, providing care in accordance with the patients' EOL preferences promotes patient autonomy and improves both patient and family satisfaction with care. To reiterate, improving patients' EOLC depends on the healthcare personnel's ability to initiate and engage in discussions with them.³⁹

Good communication between patients and the healthcare professionals is essential so that mutual rational decisions can be reached. Nurses, who are typically present at patients' bedsides, should have many opportunities to get to know the patients' preferences. Giving patients the possibility to express what they think about MV treatment and other care options when they are in a stable conditions is medically crucial as well as being a legally required right.⁷

Methodological limitations

A criticism of this study could be the relatively small sample size. The qualitative design gives limited possibilities for generalising. The study did not include any observation of what the nurses were actually doing and how these activities affected the decision-making process over time. The study was retrospective and the nurses' recollections may have altered over time, although each focus group demonstrated a unified, collective memory of the individual cases discussed. The preconceptions of both the researchers and the participants were present in both the questions raised and the interpretation. However, we aimed to maintain a balance between being close to the theme as an essential part of the generation of understanding and striving for sensitivity about unavoidable preconceptions, which involved a reflexive objectivity.²³

Conclusion

This study showed that instead of applying holistic and patient-focused approaches, the nurses found themselves operating within a cure-directed treatment culture wherein they were unable to stand up for the caring values. Nurses should be in a unique position to act as moral agents in the interface between technology and humane in patient-centred care.⁴⁰ It seems that the nurses do not fully consider their professional and ethical responsibilities. This is a serious problem for nursing ethics and role perception. Nurses should take greater responsibility for changing the interdisciplinary culture of power hierarchy and subordination to physicians that ultimately threatens patients' safety. To be able to advocate for the patients'

and their own right to be included in decision-making processes, nurses need an awareness of their responsibility. This requires personal courage, willingness and enthusiasm on the part of nurses, as well as a leadership who are capable of organising common interpersonal meetings and willingness on the part of physicians to include and value the nurses participating in decision-making processes.

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References

1. Borge CR, Wahl AK and Moum T. Pain and quality of life with chronic obstructive pulmonary disease. *Heart Lung* 2011; 40: e90–e101.
2. Gudmundsson G, Ulrik CS, Gislason T, et al. Long-term survival in patients hospitalized for chronic obstructive pulmonary disease: a prospective observational study in the Nordic countries. *Int J Chron Obstruct Pulmon Dis* 2012; 7: 571–576.
3. Gore JM, Brophy CJ and Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax* 2000; 55: 1000–1006.
4. Janssen DJ, Wouters EF, Schols JM, et al. Care dependency independently predicts two-year survival in outpatients with advanced chronic organ failure. *J Am Med Dir Assoc* 2013; 14: 194–198.
5. Buxton KL, Stone RA, Buckingham RJ, et al. Current and planned palliative care service provision for chronic obstructive pulmonary disease patients in 239 UK hospital units: comparison with the gold standards framework. *Palliat Med* 2010; 24: 480–485.
6. Izumi S, Nagae H, Sakurai C, et al. Defining end-of-life care from perspectives of nursing ethics. *Nurs Ethics* 2012; 19: 608–618.
7. *Norwegian legislation: the patients' right act*. Oslo: University of Oslo, 1999.
8. International Council of Nurses. The ICN codes of ethics for nurses. Revised ed. 2012. Retrieved from http://www.icn.ch/images/stories/documents/about/icncode_english.pdf
9. Goodridge D, Duggleby W, Gjevre J, et al. Caring for critically ill patients with advanced COPD at the end of life: a qualitative study. *Intensive Crit Care Nurs* 2008; 24: 162–170.
10. Philip J, Gold M, Brand C, et al. Negotiating hope with chronic obstructive pulmonary disease patients: a qualitative study of patients and healthcare professionals. *Intern Med J* 2012; 42: 816–822.
11. Curtis JR, Engelberg RA, Nielsen EL, et al. Patient-physician communication about end-of-life care for patients with severe COPD. *Eur Respir J* 2004; 24: 200–205.
12. Gaber KA, Barnett M, Planchant Y, et al. Attitudes of 100 patients with chronic obstructive pulmonary disease to artificial ventilation and cardiopulmonary resuscitation. *Palliat Med* 2004; 18: 626–629.
13. Hancock K, Clayton JM, Parker SM, et al. Discrepant perceptions about end-of-life communication: a systematic review. *J Pain Symptom Manage* 2007; 34: 190–200.
14. Bach V, Ploeg J and Black M. Nursing roles in end-of-life decision making in critical care settings. *West J Nurs Res* 2009; 31: 496–512.
15. Jezewski MA and Finnell DS. The meaning of DNR status: oncology nurses' experiences with patients and families. *Cancer Nurs* 1998; 21: 212–221.

16. Nortvedt P and Nordhaug M. The principle and problem of proximity in ethics. *J Med Ethics* 2008; 34: 156–161.
17. Hov R, Hedelin B and Athlin E. Being an intensive care nurse related to questions of withholding or withdrawing curative treatment. *J Clin Nurs* 2007; 16: 203–211.
18. Lind R, Lorem GF, Nortvedt P, et al. Intensive care nurses' involvement in the end-of-life process – perspectives of relatives. *Nurs Ethics* 2012; 19: 666–676.
19. Houben CH, Spruit MA, Wouters EF, et al. A randomised controlled trial on the efficacy of advance care planning on the quality of end-of-life care and communication in patients with COPD: the research protocol. *BMJ Open* 2014; 4: e004465.
20. Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345.
21. Halvorsen K, Forde R and Nortvedt P. The principle of justice in patient priorities in the intensive care unit: the role of significant others. *J Med Ethics* 2009; 35: 483–487.
22. Benbenishty J, Ganz FD, Lippert A, et al. Nurse involvement in end-of-life decision making: the ETHICUS Study. *Intensive Care Med* 2006; 32: 129–132.
23. Kvale S and Brinkmann S. *Interviews: learning the craft of qualitative research interviewing*. Los Angeles, CA: Sage, 2009, p. 354.
24. Malterud K. *Fokusgrupper som Forskningsmetode for Medisin og Helsefag* [Focus groups as a research method in medicine and health care]. Oslo: Universitetsforlaget, 2012.
25. Norwegian Directorate of Health. *Livsforlengende behandling: beslutningsprosesser ved begrenning av livsforlengende behandling* [Life prolonged treatment: decisions regarding limiting life prolonged treatment]. Oslo: Norwegian Directorate of Health, 2013.
26. Beauchamp TL and Childress JF. *Principles of biomedical ethics*. 6th ed. Oxford: Oxford University Press, 2009, 417 pp.
27. Maguire P. Barriers to psychological care of the dying. *BMJ* 1985; 291: 1711–1713.
28. Paganini MC and Bousso RS. Nurses' autonomy in end-of-life situations in intensive care units. *Nurs Ethic* 2014.
29. Mishelmovich N, Arber A and Odelius A. Breaking significant news: the experience of clinical nurse specialists in cancer and palliative care. *Eur J Oncol Nurs*. Epub ahead of print 11 October 2015. DOI: 10.1016/j.ejon.2015.09.006.
30. Kuhse H. *Caring: nurses, women and ethics*. Oxford: Blackwell, 1997.
31. Norwegian Directorate of Health. *Kols: Nasjonal faglig retningslinje og veileder for forebygging, diagnostisering og oppfølging* [COPD: national professional guidelines and guide for prevention, diagnosis and monitoring]. Oslo: Norwegian Directorate of Health, 2012.
32. Decramer M and Janssens W. Chronic obstructive pulmonary disease and comorbidities. *Lancet Respir Med* 2013; 1: 73–83.
33. McMillen RE. End of life decisions: nurses perceptions, feelings and experiences. *Intensive Crit Care Nurs* 2008; 24: 251–259.
34. Hamric AB and Blackhall LJ. Nurse-physician perspectives on the care of dying patients in intensive care units: collaboration, moral distress, and ethical climate. *Crit Care Med* 2007; 35: 422–429.
35. Kuhse H and Singer P. *A companion to bioethics*. Chichester: Wiley-Blackwell, 2009, p. XIII, 622 s.
36. Benner P, Tanner CA and Chelsa CA. *Expertise in nursing practice: caring, clinical judgement, and ethics*. New York: Springer, 1996.
37. Rodney P, Varcoe C, Storch JL, et al. Navigating towards a moral horizon: a multisite qualitative study of ethical practice in nursing. *Can J Nurs Res* 2009; 41: 292–319.
38. Baggs JG, Schmitt MH, Mushlin AI, et al. Association between nurse-physician collaboration and patient outcomes in three intensive care units. *Crit Care Med* 1999; 27: 1991–1998.
39. Le BH and Watt JN. Care of the dying in Australia's busiest hospital: benefits of palliative care consultation and methods to enhance access. *J Palliat Med* 2010; 13: 855–860.
40. O'Keefe-McCarthy S. Technologically-mediated nursing care: the impact on moral agency. *Nurs Ethic* 2009; 16: 786–796.