

# How do patients with exacerbated chronic obstructive pulmonary disease experience care in the intensive care unit?

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## How do patients with exacerbated chronic obstructive pulmonary disease experience care in the intensive care unit?

The aim was to gain insight into how patients with advanced chronic obstructive pulmonary disease (COPD) experience care in the acute phase. The study has a qualitative design with a phenomenological approach. The empirics consist of qualitative in-depth interviews with ten patients admitted to the intensive care units in two Norwegian hospitals. The interviews were carried out from November 2009 to June 2011. The data have been analysed through meaning condensation, in accordance with Amadeo Giorgi's four-step method. Kari Martinsen's phenomenological philosophy of nursing has inspired the study. An essential structure of the patients' experiences of care in the intensive care unit by acute COPD-exacerbation may be described as: Feelings of being trapped in a life-threatening situation in which the care system

assumes control over their lives. This experience is conditioned not only by the medical treatment, but also by the entire interaction with the caregivers. The essence of the phenomenon is presented through three themes which describe the patient's lived experience: preserving the breath of life, vulnerable interactions and opportunities for better health. Acute COPD-exacerbation is a traumatic experience and the patients become particularly vulnerable when they depend on others for breathing support. The phenomenological analysis shows that the patients experience good care during breath of life preservation when the care is performed in a way that gives patients more insight into their illness and gives new opportunities for the future.

**Keywords:** mask treatment, noninvasive ventilation treatment, COPD-exacerbation, patient experience, phenomenology, qualitative study, nursing, care.

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## Introduction

Patients who experience acute exacerbation of COPD have described the condition as scary and dramatic (1, 2). The main symptom, 'breathlessness', is experienced as a painful and constant struggle for air. When the exacerbation occurs suddenly and unexpectedly, the patients may experience the situation as overwhelming and feel that they 'exist' rather than 'live' (3). Living with COPD may entail anxiety, breathing problems, exhaustion and isolation (4, 5), particularly during the last part of life (6, 7).

When suffering, acute COPD-exacerbation patients are often admitted to special hospital wards for advanced medical treatment. Standard treatment for acute COPD-exacerbation is a controlled supply of oxygen, systemic steroids, bronchodilators and possibly antibiotics. Noninvasive ventilation treatment (NIV) may help the patient

through a critical phase until the medical treatment starts to take effect. NIV treatment is ventilation support treatment by a ventilator hooked up to a tightly fitting face or nose mask. The patient's breathing is supported by the ventilator which supplies air with positive pressure. Various pressure levels on the ventilator may be adjusted for breathing in and out: bi-level positive airway pressure (BPAP) (8). Several major meta-analyses and Cochrane reviews report that mask treatment, compared to conventional ventilator treatment, is less traumatic for the patient and results in fewer complications (9–12). Mask treatment may still be a challenge to the patients: Experiences of anxiety, panic and loss of control are reported. Mask-intolerance can be the result (13–15). Several factors influence the result, one of the most important being the competence level of the staff (16, 17). Studies show that nurses can help patients with COPD improve their coping techniques (18, 19), and that good care and successful treatment requires an understanding for these patients' sufferings (3, 15). Cooperation between patient and nurse is crucial for the success of NIV (20). The mask treatment shall not

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constitute a 'forced treatment'; however, the patients may be in too bad a condition for deciding what is in their own best interest. Nurses experience ethical challenging dilemmas in the acute face of COPD, and that acute phase is not a good time to raise questions concerning palliative treatment (21). The ontological aspects of human existence emerge in the concrete situation and may yield evident insights when difficult ethical choices must be made (22).

### *Purpose*

The purpose of the study was to describe experiences of care of patients with advanced COPD when suffering acute exacerbation in intensive care units. Insight into the patients' experiences in such acute and life-threatening situations may provide useful knowledge for the health care workers who administer care and treatment in these challenging situations.

### *Care philosophy*

In this study, we have chosen Kari Martinsen's phenomenological philosophy of caring as a theoretical frame of reference. Martinsen emphasises the 'sensuous-moral' encounter between human beings in which interdependence is an important factor (23). Martinsen borrows this concept from the Danish phenomenologist and theologian Knut Løgstrup. According to Løgstrup, a human being is fundamentally dependent on others. Nevertheless, life has its determined form and independence, and one human being is not the master of another (24). In critical illness, a person's autonomy may be threatened. This interdependence demands a human response in the form of care; this is the value foundation of all care. Whether care actions become 'life-enhancing' or 'life-constraining' will depend on the other, according to Martinsen (23, 25). She points to Løgstrup who emphasises the ethical life phenomena: trust, hope, mercy, openness of speech, giving and forgiving, all expressed as life utterances in human relations. These are all spatial phenomena, present in a situation. The place and the situation are embedded in a sensed space where everything in the room becomes part of the tuning of the impression. The ethical life phenomena may extend the space and give the other more room in the relation. The life phenomena are life-giving and open up to reality as it is (25). Martinsen also emphasises the articulation of impressions in which two aspects are essential: the meaning carried by the impression and the way it is received and actively worked with (22). The sensed impression must be received and interpreted if the life phenomena shall come into play in a good way. Professional judgment is a practice in being open to the sensed impression (23).

## **Methods**

Through a qualitative method with a phenomenological approach, the aim was to gain a deeper understanding of the patients' experiences of care and treatment (26). Phenomenological descriptive design was chosen as the most appropriate design for this study. Phenomenology is a relevant and proper approach to make the essence as well as variations emerges from the patients' experiences, possibly yielding increased insight into, and knowledge of, the subject (26). Phenomenology's point of departure is the world in which we live our daily lives and where we gain our experiences (27). The essence of a phenomenon may be revealed by seeing the matter from various points of view, from which the phenomena fade into each other or intertwine (27, 28).

### *Sample*

The sample was strategic and the contact nurses in the units recruited patients according to the following criteria: The patients should be diagnosed with severe COPD according to the GOLD stages 3–4. They should have had treatment with BPAP mask and represent both sexes. The patients should be asked to participate in the study after the acute treatment was completed and they had recovered to a satisfactory condition. The interview was to take place within 2 weeks of the completion of the acute treatment. The sample was made up of five women and five men between the ages of 45 to 85 – all answering to the inclusion criteria. Nine of the patients were diagnosed with COPD stage 4 and one with stage 3. Six of the patients had received their COPD diagnosis more than 9 years ago.

### *Data collection*

Data were collected between November 2009 and June 2011 at two intensive care units at two Norwegian hospitals. An interview guide with semi-structured in-depth interviews was used to collect data. The individual interviews were guided by some initial questions inviting the patients to narrate their experiences related to their encounter with the intensive care unit. They were encouraged to describe their experiences in as much detail as possible. The informants gave spontaneous descriptions, and new questions were posed based on their statements. The interview guide contained questions on how the patients experienced their situation when they were given care and treatment in the intensive care unit, in which ways they felt the staff could be of help and support during the treatment and how they experienced cooperation with the staff. Six interviews were carried out while the patients were still in the hospital and four at home within 2 weeks of discharge from

hospital. The interviews were carried out by the authors of the article, both intensive care nurses with experience with in-depth interviews. The researchers were not involved in the care and treatment of the patients. Six of the interviews were carried out by the first author and four by the second author. The interviews lasted from 21 to 49 minutes. They were recorded digitally and transcribed verbatim.

### *Ethical aspects*

The project observes the ethical principles of the Helsinki Declaration, and the study is evaluated and recommended by the Regional Committee for Medical Research Ethics and Norwegian Social Science Data Services AS (29). The principles of voluntary participation, anonymity and freedom to withdraw from the study at any time have been observed. Through a letter of information, the patients were informed beforehand of the main topics of the conversation, and informed consent was obtained through consent forms from patients and in cooperation with the hospital ward administration.

### *Analysis*

In the data analysis, Amadeo Giorgi's (26) empirical four step method was used as a point of departure for condensation of meaning. The transcribed text was first read through several times to gain an overall impression of the informants' experiences. Based on this understanding, the units of meaning were identified. For each interview, the text was organised into various themes with the same meaning content. The text was systematised based on the questions to the text material on how the patients experience care and treatment in the acute situation. At the third step, each unit of meaning was abstracted to a higher level with new, more appropriate, concepts, while the meaning was preserved. At the final step, a summary was written, describing what was specific and general, based on all the interviews. Finally an essential structure of the phenomenon was composed in which three main themes and patients' statements illustrate the essence and describe variations in the phenomenon. The first author has written the analysis of the interviews. The authors have cooperated closely through all phases of the research process.

## **Results**

The results of the in-depth interviews with ten patients with severe COPD reveal an essential structure in the patients' experience of care and treatment in the intensive care unit. This structure may be characterised as the feeling of being trapped in a life-threatening situation in which the care system assumes control over their lives.

This experience is conditioned not only by the medical treatment, but also by the entire interaction with the caregivers. The essential structure is presented through three central themes: preserving the breath of life, vulnerable interactions and opportunity for better health.

### *Preserving the breath of life*

The majority of the patients described horrible experiences of heavy breathing, much mucus and difficulties with getting enough air. Being unable to speak, unable to act, not being able to eat, feeling ill all over were other experiences. Getting sufficient air was crucial: 'I fought bravely, and it is so hard and so painful to breathe. It is like breathing through a straw and then it is suddenly cut off.'

Mental strategies for relaxing through disconnecting all thoughts, calming down and trying to breathe normally could help: 'Doctor Larsen once told me: Try to disconnect; don't think. If you can do that it will be a great help. Feeling anxious and having COPD and breathing problems – this is not good'.

Feeling safe in the situation gave a feeling of mastery. It was essential for one patient that the staff knew what to do and that the doctor was present with a treatment plan. Another felt that being able to call for help was crucial. Not being understood while being wholly dependent on help from others was described as inducing hallucinations. If she lost control and felt trapped, she experienced seeing strong colours and scary faces. It gave a feeling of control when health care providers were in control of the situation and personal wishes were fulfilled and respected: 'That you feel you are in safe hands – that there is control over what is being done and that they know what they are doing – this is transferred to the patient if he is conscious enough to pick up on it'.

To feel that the BPAP mask opened up for more air was a decisive factor, and gave a feeling of security and control. Familiarity with masks from earlier occasions and proper instructions from the nurses and doctors on how to breathe with the mask were also helpful. Several patients felt that the mask saved their lives: 'I regained my freedom, I could breathe, gradually, at first just a little and then, finally, quite well'.

The patients say that different masks gave different kinds of relief. The mask treatment was also described as evoking anger. The mask and the ventilator also gave a feeling of breathlessness.

### *Vulnerable interactions*

Positive encouragement from supportive and dedicated nurses and physicians gave motivation to endure the treatment. One patient said that even though the staff did not have a lot of time he felt they did what they

could to ease his breathing difficulties: 'I had only one purpose; to breathe. And they helped me with that as best they could'.

Another patient described how good it felt to be helped with all the little things one is in constant need of when seriously ill. It felt good to be propped up with pillows and get good care. To be met as a fellow human being by nurses who understood, was important. One patient, who initially did not want to be admitted to hospital, said he felt so safe and well taken care of. It was so good to be in the intensive care unit that he did not want to be moved, in spite of much discomfort. That the staff displayed a sense of humour, even when the situation was serious, speeded up one patient's recovery. Several patients emphasised how safe they felt when the nurses were there the whole time. To be able to chat with physicians was good. The way the staff behaved and the way they chatted with the patient influenced the patient's feeling of worth: 'They were very helpful and paid close attention – and kind. They would almost see my needs before I did'.

Some patients felt 'ignored'. One patient felt treated like a 'commodity' and not like a human being. A woman who had struggled with the illness for a long time said she was happy to receive help but that she felt she was a nuisance. She said she was put 'on hold'. Feeling not seen and heard induced aggression. They did not take her seriously and she felt a lack of respect: 'They did not take me seriously. When I am not heard, or unable to express my opinion, I get livid. Anger comes with the illness'.

The importance of being seen or heard was described by several participants. One woman described her anxiety at feeling locked up in her room. The doors must be open and the curtains open. Being alone was sometimes difficult. One patient said he became anxious when the nurse left him with the mask on. For another patient it was quite crucial to be seen in the acute phase. During the night, she would lie in bed with the bell-push in her hand and the door open, otherwise anxiety would overwhelm her. Having the doors open was important also after the patient's condition had improved and one was increasingly left to one's own devices: 'I didn't like being in the room. It was horrible with the doors closed, I felt safe out among people'.

Having confidence in the nurses was important for feeling safe in the treatment situation. One patient said that he was completely dependent on being able to trust that what happened was what was best for him. Knowing that the nurses knew 'their stuff' and could act when and if necessary, gave a feeling of trust.

Mistrust arose when the patient was worried about not being properly looked after. One patient did not dare to accept a sleeping pill and was unable to sleep. Family and physicians discussing further treatment above the patient's head evoked feelings of mistrust in the patient.

### *Opportunity for better health*

Feeling respected by the staff gave increased self-control and feelings of being included in the treatment situation. One patient said he trusted the physicians and left to them all that had to do with his treatment. He did not have any need to participate more. Good relations were also seen as invitations to participation: 'I participated all the time and most of them were encouraging and open. They listened to what I had to say – what little I had to say'.

Some patients felt 'left out'. One patient said she did not dare express her opinion. Being ignored felt degrading. She felt she was of little worth. Another patient wanted the staff to cooperate more. He knows his body and knows how he is doing – and he wanted the nurses and physicians to show more interest in this: 'Listening to the patients is really important. The staff doesn't know how little one can take when one suffers from severe COPD like I do'.

How the patients experienced being given and receiving information varied. One of them remembered poorly what was said, but it was said in an encouraging way and that made an impression. It was important to have room for asking questions and receiving answers: 'I have not said all that much. I have asked. They have listened to what I have said. I want to know and I have received answers to what I wanted to know: I want to know the gravity of my illness'.

In the acute phase, the patients experienced an altered state of consciousness. One patient described his condition as being in a dream world and having an experience of 'losing his life'. Existential thoughts emerged for the patients in their critical situation. Relatives were important 'go-betweens' and communicators between patients and the intensive care unit. What was real and imagined could become clearer through the relatives. One patient said she felt so unsafe in retrospect remembering that relatives had to work hard to get her ventilator treatment when the physicians had decided there was no point in trying. 'The doctors just wanted to ease her death', she said. Not knowing whether she would get treatment again and not having any say in the matter made her feel uncertain about the future.

Several patients felt they were quite competent with regard to 'their' COPD, but were unsure as to what provokes exacerbation. One patient said her mental state was so reduced when she was in the hospital that she was unable to ask the questions she really wanted to. When she came home she had unanswered questions: 'My mind just wasn't quite clear. I just said: good morning, hello and thank you. I didn't talk about anything then. I was just content'.

The patients described challenging processes towards increased self-understanding during the stay at the intensive care unit. Some described the staff as focusing only

on COPD and smoking, and the treatment was at times experienced as a punishment for a self-induced disease. Several patients said they had become more motivated to change their lifestyle. They wanted to quit smoking and exercise more. They had received the help the staff could give and wanted to assume responsibility for their further life.

## Discussion

A phenomenological analysis of ten patient interviews has yielded new and interesting understanding of how patients may experience care and treatment during acute exacerbation of COPD. The findings show that the patients experienced themselves as being in a state where life was about to end. The experience of being wholly dependent on others actualises Kari Martinsen's use of the 'interdependence' concept; a human being's dependence on fellow human beings is a fundamental life phenomenon (23, 25). Our existence depends on being received by 'the other'. In critical situations the patient is at the mercy of the staff and wholly dependent on breathing support. This renders life vulnerable. From this situation of vulnerability, caretakers are ethically appealed to care for what one has been entrusted (25). Like some other studies point out, the patient's vulnerable physical state, requiring such a struggle for 'the breath of life', demands advanced technical equipment and good professional nursing competence (15–18). This study shows that the patients were totally dependent on the medical technology. When the vulnerable body, fighting for air, was given a mask and breathing support, this was experienced as freedom. BPAP mask and ventilator become 'lifesavers', helping the patients survive. Patients with COPD describe this acute air shortage as extremely painful and uncomfortable both in this study and earlier research – and say staff do not always show sufficient understanding of this experience (3, 20).

As in earlier research, anxiety associated with COPD-exacerbation is described as a factor worsening the patient's condition (1, 2, 15, 17, 18). Findings in this study point to a possible lessening of anxiety through several coping strategies, and faith in one's own ability to cope should receive greater focus. This is also emphasised in earlier research (17–19). Familiarity with the mask treatment was of great help, and it is therefore a potential gain in giving the patients some training beforehand. The findings show that the patients need to trust that they will be helped. They experienced trust when they were met by competent staff in control of the situation. Interdependence and the 'breath of life' are safeguarded. Dependence and 'breathlessness' are central themes also in Lomborg et al.'s study of patients with COPD in hospital, emphasising that patient care may be improved by adapting it to the patients' needs and strategies (17, 18).

The experience of forced treatment, violation and mistrust show that the ethical demand for care is not sufficiently responded to. Becoming angry, not being understood and being unable to trust the nurses express negative emotions and a lack of trust. When the patients are unable to trust the staff this may, according to Martinsen, destroy the patients' life courage and life joy (23).

There is a continuous articulation of impressions in the relation between the critically ill patient and health care personnel. In the treatment and in the nursing, a 'vulnerable interaction' is at play. According to Martinsen, the ethical demand for safeguarding the life of the other has its source in the sense impression. When the nurse is sensitively present in the situation and experiences and interprets the patient's impression, trust is put into play in a beneficial way (23, 25). Care as a life-enhancing or life-violating relation emerges through the patients' experiences in the study. When the nurses 'recognised the needs before the patient did', this point to the nurses showing great sensitivity and interpreting the patients' impressions in a good way.

The patients sensed the nurses' expressions continuously: the way the nurses acted and the way they spoke to the patients and whether the nurses were present and dedicated. That the doors were open, the curtains pulled away from the windows, that the patients were seen and heard all through the critical situation point to a great need for sensitive presence. When the patient heard physicians and relatives discuss the serious situation without heeding the patient's presence, the conditions for establishing trust in the relation were not present, according to Martinsen (23, 25). Anxiety, claustrophobia, anger, feeling like a commodity, all these are expressions for the patient feeling ignored. The appeal to be received by 'the other' was not met, and trust could not grow. Was it due to busyness, in which there is no room and time for the work of understanding and which may lead to a drying up of the senses (25), or was it a lack of ethical competence where the nurse has more than enough with handling the demanding technical equipment? The sensitive nurse sees with 'the eye of the heart', with his or her whole body, which is touched (30). It is an interactivity of the senses in which the nurse is compassionate and interpretive and uses his or her professional competence so that the patient feels cared for. Phenomenology is a way of thinking in order to see the meaning which rests in the tuned impression for them to understand and express it (22, 31). In this study the patients' experiences show that when their sense impressions are interpreted and understood, the nurse acts in a manner which creates trust and the NIV treatment may succeed. A theoretical model by Sørensen presents different forms of cooperation used by nurses when helping patients with NIV treatment (20). Sørensen's model may yield useful insights into practice along with phenomenological

philosophy. Findings in this study show that good forms of cooperation have their points of departure in a sensitive understanding of the concrete situation, otherwise the cooperation becomes faulted. Through the phenomenological method, opening up to the ontological level, the proper and best form of cooperation may become evident (23, 32).

Ontological evidence makes it possible for the 'real' reality to emerge and the nurse gains insight into how best to meet the patient and act in the care situation for him (22). The study shows that the patients have 'room' for the staff and wish that they were more interested in the patient's knowledge of his or her own COPD. When the patients felt treated like a 'commodity' or felt ignored, there was little room for beneficial interaction.

The study also shows that the patients see hope in an uncertain future. The wish for a change in lifestyle, becoming motivated to quit smoking, being more physically active and taking their disease seriously, became actualised. A feeling of being included in their treatment made several patients feel more open to receiving information. According to Martinsen, the ethical life phenomena may expand the room and give the other more space in the relation (25). When the physician met the patient in a satisfactory way, the patient felt cared for and became motivated to make changes to his lifestyle. Then the health care workers create space for trust to grow (33).

The patients' descriptions of their mental state when critically ill, point to the existential conditions in which the breath of life is felt in the body as a fundamental phenomenon of life. They are in a critical 'breathing space' where they are also aware that life has its limits. Expressions like 'being put on hold' may point to an experience of being in the final stages of life (34). Earlier research point out that patients with severe COPD stage 4 have a shortened life expectancy, without much focus being put on the fact that they may be in the final stages of life. The focus is on survival and treatment rather than possible death (35). That the nurses and physicians maintain a palliative perspective along with administering emergency treatment may give the patients improved care and support (7, 36).

The study shows that some patients found it difficult to formulate questions while they were critically ill. Did the patients not understand the information because they were 'left out', or was it the feeling of guilt from suffering from a possibly self-induced disease that kept them from seeking sufficient information? When several patients describe the staff as having insufficient understanding of COPD, this is consistent with Halding's research which shows that nurses have an important role in helping the patients in the process of overcoming their feelings of guilt and must take care not to reinforce this

guilt (37). Research shows that patients in the acute stage do not dare to look ahead (6). The difficulties some have with accepting the COPD diagnosis point to a need for time and space. Beneficial care yields space for participation and real commitment to the other: space for moving between sensing and understanding, according to Martinsen (25). Insight arises in the space between sensing and understanding for nurses and patients both (25, 31). The study shows that when the patients feel included and cared for, more space emerges for increased knowledge and understanding of the illness they live with.

#### *Limitations of the study*

The findings represent patient experiences from an acute and life-threatening condition. Several patients say they were in an altered mental state and do not remember all from the acute stage. The patient's vulnerability and their dependence of care might have led to that important information about care and treatments that are not communicated.

The empirics nevertheless represent a rich material that yields useful insight into the patients' experiences of their critical condition.

#### **Conclusion**

The study shows that the patients' experience of the quality of the care and treatment they receive from nurses, who meet their needs for breathing support, is essential. Gaining more understanding of the patients' experienced struggle for breath and the anxiety which threatens their control over their own lives may have significance for how the staff helps the patients tolerate emergency NIV treatment. Phenomenological analysis of patient experiences shows that when help to preserve the breath of life through medical technology is being administered with 'sensitive' care, the patients feel safe. In this way, the intensive care unit may constitute good 'breathing spaces' where the patients regain the 'breath of life' in rhythm and is able to discover opportunity for better health. Knowledge of patient experiences during COPD-exacerbation and the necessity of good 'sensitive' interaction should be a topic in nursing education and medical education. The collaboration between nurses, physicians and patients should be strengthened to meet the patients' demand for care and treatment during the next exacerbation.

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## Author contributions

Design: Henny Torheim and Marit Kvangarsnes, data collection/analysis: HT and MK. Drafting of manuscript: HT, critical revisions for important intellectual content: MK.

## Ethical approval

This study was a part of a larger research project approved by the Det medisinske fakultet Regional komite

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