

## Narratives of breathlessness in chronic obstructive pulmonary disease

Marit Kvangarsnes, Henny Torheim, Torstein Hole and Lennart S Öhlund

**Aims and objectives.** To explore patient perceptions of chronic obstructive pulmonary disease exacerbation and the patients' experiences of their relations with health personnel during care and treatment.

**Background.** Patients suffering from acute exacerbation of chronic obstructive pulmonary disease often experience life-threatening situations and undergo noninvasive positive-pressure ventilation via bi-level positive airway pressure in a hospital setting. Theory on trust, which often overlaps with the issue of power, can shed light on patient's experiences during an acute exacerbation.

**Design.** Narrative research design was chosen.

**Methods.** Ten in-depth qualitative interviews ( $n = 10$ ) were conducted with patients who had been admitted to two intensive care units in Western Norway during the autumn of 2009 and the spring of 2010. Narrative analysis and theories on trust and power were used to analyse the interviews.

**Results.** Because of their breathlessness, the patients perceived that they were completely dependent on others during the acute phase. Some stated that they had experienced an altered perception of reality and had not understood how serious their situation was. Although the patients trusted the health personnel in helping them breathe, they also told stories about care deficiencies and situations in which they felt neglected.

**Conclusions.** This study shows that patients with an acute exacerbation of chronic obstructive pulmonary disease often feel wholly dependent on health personnel during the exacerbation and, as a result, experience extreme vulnerability.

**Relevance to clinical practice.** The findings give nurses insight into building trust and a good relationship between patient and caregiver during an acute exacerbation of chronic obstructive lung disease.

**Key words:** COPD exacerbation, interviews, narratives, patient experiences, patient participation, trust

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### Introduction

The World Health Organization (WHO 2012) predicts that chronic obstructive pulmonary disease (COPD) will be the third leading cause of death worldwide by 2030. There is at present no known cure for this progressive illness, and most

patients suffering from this disease will occasionally experience an acute exacerbation (Elkington *et al.* 2004, Miravittles *et al.* 2007). An exacerbation can be a life-threatening situation, and in some parts of Norway, patients with an exacerbation are admitted to intensive care units (ICUs) where they undergo noninvasive positive-pressure

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ventilation via bi-level positive airway pressure, which is a common treatment worldwide (Keenan *et al.* 2003, Ambrosino & Vaghegghini 2007). In other countries, this type of care is delivered in high dependency units, acute respiratory units or other facilities.

Successful treatment for acute exacerbation of COPD requires good understanding and interaction between the patient and health personnel (Torheim & Gjengedal 2010). In Norway, intensive care nurses are often involved in managing the prescribed treatment; hence, it is vital that they possess the knowledge necessary for providing quality care to patients who experience breathing problems during the acute phase of this disease. Health personnel must be qualified in this respect so as to render health services to this large group of patients. Norway, with a population of nearly 5 million people, is estimated to have about 200,000 people with COPD (Ministry of Health & Care Services 2006).

## Background

Research has revealed that patients diagnosed with COPD have to live with many of the symptoms of the disease. This section examines review studies that have investigated COPD from the perspective of patients and caregivers, with a special focus on acute exacerbation. Because theory on trust and power is used to analyse data in this study, this theory is also presented.

Breathlessness has been reported to be the worst symptom of COPD (Kessler *et al.* 2006, Gardiner *et al.* 2010). Research studies have shown that breathlessness restricts the freedom of patients who suffer from COPD by impairing their mobility and that it is linked to anxiety and panic (Elkington *et al.* 2004, Andenæs *et al.* 2006, Miravittles *et al.* 2007, Gardiner *et al.* 2010). Miravittles *et al.* (2007) conducted a survey to obtain information on patients' perceptions of their COPD and exacerbations and their expectations about treatment. The most frequent complaints of patients were that they could not complete their activities (54%) and that they were afraid that their COPD would cripple or eventually kill them (17%). Barnett (2005) also determined breathlessness to be the worst symptom of COPD and that it leads to anxiety, panic and fear. In addition, Barnett (2005) described how patients with COPD experience loss of role within the family and intimacy in personal relationships. In a quantitative study of patients with COPD, patients reported that a feeling of fatigue was always present and that they regarded it as either the worst or one of the worst symptoms they had (Theander & Unosson 2004).

Torheim and Gjengedal (2010) found that patients with COPD whilst undergoing mask treatment felt they were

trapped in a situation of complete dependence on others. Anxiety, panic and loss of control also characterised this situation. Regaining control and trust through skilled help and mobilisation of willpower were regarded as important.

Through their analysis and discussion of two case studies of acute episodes of COPD, Bailey and Tilley (2002) illustrated the meaning-making function of stories of chronic illness. They stated that patients' stories provide access to a subjective reality – that is, the patients' truth and the meaning of their experiences. Different meanings were drawn from a story that was told twice. Through a 'death story', a patient communicated that he did not trust the nurse providing him with care to recognise the seriousness of his distress and that he lived with an overwhelming fear of death during episodes of acute breathlessness.

Bailey (2004) examined the affective component of dyspnoea/anxiety as described by patients with COPD and their family caregivers. She suggested that healthcare providers must consider an alternative understanding of the 'anxiety–dyspnoea–anxiety' cycle. In her study, anxiety was not usually the underlying cause of distressing dyspnoea but rather a sign of longstanding or acute respiratory failure. The underlying experience of patients was shortness of breath, an experience that was essentially subjective and undetectable. These patients had learned to control their emotional reactions. When patients feel anxious, this emotion is an indicator that they are actually breathless. Bailey (2004) emphasised the importance of nurses being able to recognise anxiety as an emic sign and not necessarily the cause of dyspnoea for patients with COPD in acute respiratory distress.

## Trust and power

Trust is a central concept in understanding the relationship between caregiver and patient during COPD exacerbation. Grimen (2008) examined the meaning of trust in a professional context, focusing particularly on the relationship between patient and professional. According to Grimen (2008), the two most important perspectives on this relationship are what the trust-giver/the patient *does* and what *trust* does in the relationship *between* individuals: 'What trust does in relations is built on what trust-givers do, viz. to give something into others' care in good faith' (p. 197). Trust, however, can be violated. It thus represents an element of power in all help and care relationships. Many situations imply that patients empower and confer trust to health personnel to decide what kind of treatment should be administered. The patients presuppose that the caregivers will act in the patients' best interest. This kind of trust-based

relationship is, in the end, necessary to create the space they need to fully use their professional competence. This trust not only forms the basis for the exercise of benign power, but also makes the trust-giver/patient vulnerable to both benign and ill-natured power (Grimen 2009, p. 55).

The relationship between professionals and patients is characterised by various forms of asymmetry. Whereas professionals have both theoretical and practical knowledge, patients usually have neither. In addition, professionals are gatekeepers, and, as such, they control access to benefits. By contrast, patients lack this type of control (Terum 2003). The relationship between professionals and patients may also be characterised by elements of coercion or force. Situations where these elements exist in turn create difficult dilemmas. The alternatives to providing medical assistance by use of force may be life-threatening (Grimen 2008). Additional problems may arise based on the fact that patients with serious diseases often may be cognitively weakened and, thus, have problems expressing themselves verbally.

## The study

### Aim

This study was conducted to explore patient perceptions of COPD exacerbation and the patients' experiences of their relations with health personnel during care and treatment.

### Design

Narrative inquiry was used as an approach to obtain access to patient experiences with acute exacerbation. Ten in-depth interviews were conducted with patients who had been admitted to two different ICUs in Western Norway. Narrative analysis, which focuses on textual meaning and language form (Kvale & Brinkmann 2009), was used to examine the data.

### Narrative inquiry

Narrative inquiry has been described as a subtype of qualitative inquiry. Chase (2005) defined it as 'an amalgam of interdisciplinary analytic lenses, diverse disciplinary approaches and both traditional and innovative methods – all revolving around an interest in biographical particulars as narrated by one who lives them' (p. 651). According to Chase, contemporary researchers use five analytic lenses to approach empirical data: (1) retrospective meaning making (i.e. a narrative is communicated from the narrator's point

of view), (2) narrative as verbal action (i.e. something that is done or accomplished), (3) narratives that are both 'enabled and constrained by a range of social resources and circumstances' (p. 657), (4) narratives treated as socially situated interactive performances and (5) narratives in which the researchers view 'themselves as narrators as they develop interpretations and find ways in which to present their ideas about the narratives they studied' (p. 657). All these approaches have influenced the present study.

### Participants

Purposive sampling (Morse & Richards 2002) was used to recruit participants for this study. To increase the diversity of the participants, we included both men and women of different ages and social backgrounds. The inclusion criteria were as follows: (1) men or women and patients between 30 and 85 years and (2) patients who had been diagnosed with Global Initiative for Chronic Obstructive Lung Disease (GOLD) class 2–4 and had recently experienced exacerbation and received mask treatment in an ICU for more than 24 hours. Research information that was mapped included the following: gender, ethnic background, marital status, occupation, length of time since diagnosis and number of previous hospitalisations with acute exacerbation. This information was provided by the patients.

The patients were asked face-to-face by nurses in the ICU to which they had been admitted whether or not they wanted to take part in the study. Ten patients were interviewed once during the period of autumn of 2009 and the spring of 2011. The interviews were conducted in the ICU, in another unit or at home with the patient. Only the patient and the interviewer were present during the interview. Because several patients still experienced breathing difficulties, this problem had to be taken into consideration when designing and organising the interviews. Hence, the interviews could not be overlong, and medical help had to be readily available during the interviews. The 10 patients (five men; five women) who participated in this study were between 45 and 85 years. All 10 patients were Norwegian but possessed different social backgrounds. All the informants had had a COPD diagnosis for 0–10 years. Only one of them had never before been hospitalised with COPD exacerbation. Six of them were married and lived with their spouses. Four were single and none had higher education.

### Data collection

The study was carried out by four researchers. Two worked in a health enterprise and two at a University college. All

four cooperated with one another during the entire research process, but only two of them [both of whom were registered nurses (RNs) and had experience conducting patient interviews] carried out the interviews.

An interview guide was developed based on the aim of the study and the theory of narrative inquiry (Chase 2005) and trust and power (Grimen 2008, 2009). It had open-ended questions on how the patient had experienced the acute exacerbation and the interaction and relationship with the health personnel who took part in the treatment (Kvale & Brinkmann 2009, p. 143). These were the main questions areas:

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1. How did you experience the COPD exacerbation and your hospitalisation in the ICU?
  2. How did you experience the care and treatment you received in the ICU?
  3. How did you find the cooperation with the health personnel?
  4. How did you experience your relation with the health personnel during care and treatment?
  5. Is there anything else you want to tell?
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On the whole, the questions were an invitation to the patients to share their experiences with the interviewers, and a point was made not to pressure the patients into telling something they did not want to tell. Because the conversation was mainly about a life-threatening situation, questions about patient participation were asked in an indirect way. If this topic did happen to come up during an interview, we asked follow-up questions when it felt appropriate.

The interviews lasted between 30 and 60 minutes. They were audio recorded and then transcribed verbatim by the interviewers. Data saturation was discussed during the interviews, and after all 10 interviews had been transcribed. Both men and women of different ages and social backgrounds were interviewed. Together, the interviews represented a rich and varied set of data. The themes were illustrated with examples that showed patterns and individual variations. When the data tended to become repetitive and redundant (Morse & Richards 2002, Polit & Beck 2008), we considered the data to be saturated.

## Analysis

The transcribed interviews were first read focusing on the complexity and multiplicity within the narrators' voices (Chase 2005, p. 663). Data were coded in proportion to the patients' stories about their exacerbations and their interactions and the relations with the health personnel. The researchers discussed what the stories 'really' were about

and turned to what kind of questions that opened up new ways of understanding patient perceptions of COPD exacerbation and their relations with health personnel during care and treatment. Text analysis centred on vocabulary and grammars was used for researching the language used in the interviews in relation to power and trust (Fairclough 1992). Next, it was focused on the connections between the various stories. A plot was constructed from the coded data. According to Polkinghorne (1988), a plot is 'the organising theme that identifies the significance and the role of the individual events' (p. 18). The function of a plot is 'to transform a chronicle or listing of events into a schematic whole by highlighting and recognising the contribution that certain events make to the development and the outcome of the story' (Polkinghorne 1988, p. 18–19). In the present study, data were constructed as a story with two main themes: (1) breathlessness and (2) trust and power. The analysis alternated between working with theory of trust and power (Grimen 2008, 2009) and working with data. The ten interviews were rewritten and compiled into one story to represent the study's data (Kvale & Brinkmann 2009).

## Trustworthiness

The researchers' decisions are explicitly and carefully described to enhance the trustworthiness (Morse & Richards 2002). Transparency will offer the readers opportunities to review the decisions in the research process (Polit & Beck 2008). Two of the researchers, who were intensive care nurses with formal interview research training, conducted the interviews. Shortly after, the interviews were listened to and transcribed verbatim. The various stages in the analysis of data and the researchers' theoretical positions are described to increase credibility in the interpretation of data. Credibility was established by using quotations that showed patterns and variations in the transcribed interviews. The analysis was discussed with and confirmed by all the co-authors. Probably, some of the findings in this study may be transferred to other vulnerable patient groups highly dependent on the care of health personnel, for example other patients in acute situations.

## Ethical considerations

The study was approved by the regional committee for health research ethics (4-2008-2869). The Data Protection Official for Research also approved the study. The researchers cooperated with contact nurses in ICUs in the recruitment of patients to the present study. The patients were informed that their participation was voluntary and that

confidentiality was secured. The contact nurses also made it clear to the patients that they could withdraw from the study at any time. The participants received both written and oral information about the study, and only those who met the inclusion criteria and gave their informed consent were involved in the study. Before carrying out an interview, the researcher checked with the nurse caring for a patient to determine whether or not the patient was physically able to take part in the interview. Following the interview, a healthcare worker offered medical assistance to the patient if necessary.

## Results

The results show how 10 patients who had recently had an acute exacerbation of COPD and had received mask treatment experienced this acute phase and their relationship with health personnel during treatment in an ICU. Two main themes emerged, and they were breathlessness and the trust/power dimension. The two themes were closely related and had an inner context. We found that breathing problems led to a situation where patients experienced both situations of trust and power. Subthemes were also identified that showed story patterns, which in turn provided a more detailed understanding of the main themes.

### Breathlessness

One pattern that emerged from the data is the patients' perception that having breathing problems was the main reason for their admittance to an ICU. The patients expressed that their illness made them feel totally dependent upon the care of others.

#### *Completely dependent on the care of others*

Most of the informants remembered little from the acute phase. The phrase 'I don't remember anything' is illustrative for what many of the informants said. Other typical statements included the following: 'It was terrible. I was more or less completely gone' (N8), 'It is a matter of life and death – you got to get enough air' (N6) and 'I was completely paralysed' (N2). The statements convey a sense of being completely dependent on others. In the following interview excerpt, one informant describes a traumatic situation:

Researcher: What happened when you got the exacerbation?

N8: After I got the attack, I stood there for about three to four hours without being able to do anything, not call, nothing.... So, if my wife hadn't called ... she was at work. I managed to pick up the phone and said she had to come.

It was this man's belief that he was able to get in contact with the health service because his wife had called him. The patients had experienced increasingly heavy breathing before being hospitalised. Several said that because they did not understand the seriousness of their situation, they did not feel any particular anxiety. One patient, who had been diagnosed with COPD for a long time and who felt mentally able to cope with the acute exacerbations, remarked, 'At hospital, they say that I am calm, and I think I cope with it fairly good. They say so, the people in the ambulance. They say I am the calmest COPD patient they ever had' (N10).

#### *Altered perceptions of reality*

Several patients noted having nightmares during an exacerbation. One patient used a drowning metaphor to express how he had experienced the situation:

It seems like you enter a kind of dream world. You are at the bottom of a pool, and you want to get to the surface, but you are not able get up. You just lie there unable to breathe without being able to get to the surface. (N6)

Another patient described her phantasms as follows:

In the evenings, there was a woman with one ball down on the floor and one on the ceiling, and then she [would] spread a net with all the colours of the rainbow. I particularly remember black and bright blue. She frightened me, and, afterwards, I did not allow them [the healthcare workers] to turn off the light or the TV because I was so afraid that this woman should return to make her net again. It was scary. (N7)

Other informants said that colours, furniture and people appeared distorted during an exacerbation. When describing these incidents, patients typically used negatively loaded words and phrases, such as *frightening*, *scary*, *ugly*, *choking* and *not able to breathe*.

### Trust and power

All the informants described situations in which they had to trust health personnel. But trust implies power, and if power is misused, distrust will be the consequence.

#### *Trust*

One patient (N2) stated, 'Yes, I just had to give in. I was totally dependent upon that what was about to happen with me, would be in my best interest'. Another patient (N9) described the situation as follows:

I had to start mask treatment at once. Now there is no resistance, so, perhaps, it is better that they [health personnel] are determined.



If you get choking sensations, then ... But when it comes to breathing, fear is the worst enemy. If you ever notice [that] you lack something, it will be air. You are now about to suffocate!

The patients noted the degree of professionalism displayed by nurses and doctors when administering mask treatment. With regard to breathing assistance, they expressed complete trust in the health personnel in the ICU. The patients used expressions like *first-class cooperation* to convey their gratitude for the assistance they received in a life-threatening situation. Several patients expressed the opinion that the nurses working in the ICU had a higher degree of competence than those in other units. All patients had a positive experience with the mask treatment. One patient (N5) commented, 'I think that [the] mask [treatment] was very good for me; it really eased the pressure in my chest'. Another patient (N6), noting the helpfulness, kindness and attentiveness of the nurses in the ICU, made the following insightful comment: 'They saw my needs before I noticed them'.

Patient participation during treatment in the acute phase is often difficult. The patients in this study experienced situations in which they lacked control. Several patients expressed complete trust in the health personnel in the ICU and wanted them to make decisions regarding the administration of treatment. Even though the patients relinquished control of decision-making about treatment to the health personnel, they still were able to interact positively with the nurses and to participate actively in much of what was happening to them.

#### *Distrust and power*

In addition to stories of trust, patients in the present study revealed those of distrust. Specifically, they described situations in which they had not been administered medication they felt that they should have had and had received promises of food from the health personnel that were not fulfilled. One patient (N3) described a night on the ventilator as follows:

They would give me sleeping tablets because I had not been sleeping well. But I am a sound sleeper, so I thought it was not necessary. But she [the nurse] threatened [me] a bit with that tablet. I said no. I wanted to be attentive because I might be choked if they do not suck out the slime [in time]. I had to be in control; I just could not be asleep. 'Oh no, this is not necessary', the woman said. 'I will look after you all the time'. During the night, I did start to get blocked, and [at first] I thought I was not going to say anything —[I had planned to] just test her out to see if they looked after me. They did not. I had to call. I had not taken a sleeping tablet. I was very blocked with a lot of slime.

In her story about the nurse, the patient used the word *threatened*, which expresses strong modality and, in this context, clearly describes the pressure the patient felt in this situation. As evident from the story, the patient initially distrusted the nurse and, thus, felt that she had to test the nurse before she could trust her. However, by failing to show up when the patient needed someone to suck out the slime, the nurse did not pass the simple 'test' that the patient had devised. Another patient (N7) described a situation in which she did not have access to an alarm:

[The] most important [thing] to me was the alarm. It had to be with me all the time... There were some nurses who managed to use it to manipulate me – to get some peace, of course – and that was scary because I could not talk. My only way of getting help was through that alarm.

In this story, the patient used the word *manipulate* to express how she perceived her interaction with the nurse. From this patient's perspective, the alarm represented not merely the only means by which to summon help but also a sense of security.

One patient (N4), who felt that she was not getting the kind of care she needed because she did not have the 'right' disease, made the following remark: 'My disease was my own fault, so this served me right. I felt ... just like that now and then'. The same patient (N4) also described a typical situation in which she felt that the health personnel patronised her because she had impaired hearing: 'And when a doctor stands over you, at the same time making eye contact with a nurse and smiling, thinking I could not hear anything, well that's not nice. An educated man should know better than that'. A different patient (N1), who told a similar story about not being taken seriously, made the following comment: 'They neglected me and ignore what I say'.

One patient (N2) recounted a situation in which she believed that the health personnel had been too forceful in administering the mask treatment. Feeling that she had lost control over her own treatment, the patient became angry. From this patient's perspective, a doctor and a nurse had exercised too much force in administering treatment. During the interview, she called upon all health personnel to listen to patients in situations such as this one.

## Discussion

### Limitations

The aim of this study is to explore the experiences of patients suffering from acute exacerbations of COPD and

their relationship to health personnel during care and treatment in an ICU. The patients were well aware that their condition may have influenced how they have perceived the situations of which they described. In this respect, the data represent the patients' subjective perception of what happened. The interviews were transcribed and then translated from Norwegian into English; the patients' statements were studied to interpret the meaning behind them (Czarniawska 2004, p. 55). The responsibility of interpreting the findings was assumed by the first author of this paper. Because the first author is an intensive care nurse, her proximity to the field may have influenced the interpretations. However, the interpretations were scrutinised by the other authors of whom two had other professions. The use of an explicit theoretical framework for interpreting data was considered important in this study (Grimen 2008, 2009). Theory on trust helped to highlight some of the central findings.

### Discussion of findings

It is no surprise that the patients identified breathlessness as the most important symptom of an exacerbation and the main reason for calling a doctor. Previous studies have reported breathlessness to be the greatest problem experienced by patients with COPD – both in daily life and during an acute exacerbation (Barnett 2005, Andenæs *et al.* 2006, Gardiner *et al.* 2010, Gysels & Higginson 2010). This study showed individual variations in the narratives of patients who have experienced breathing problems. This result is in accordance with the findings of Bailey (2004), which indicated that patients with COPD learn to cope with their COPD exacerbations emotionally. In the present study, several patients conveyed that they manage to keep calm and that the situation is characterised more by the breathing problem than by anxiety. Our analysis shows some characteristics that have not previously been sufficiently highlighted in the literature. A COPD exacerbation usually results in patients having to put their lives – and often decision-making – in the hands of health personnel. A previous study of intensive care nurses' views on patient participation during COPD exacerbation reported the same finding; that is, there are situations characterised by a low degree of patient power and patient participation (Kvangarsnes *et al.* 2013). Dealing with these types of situations is ethically very demanding for caregivers because they may have to act in a way that prompts the patient to lose all trust in them. According to Norwegian legislation, the use of force by health personnel is allowed if it is necessary to administer proper treatment. In 2009, the Patients' Rights Act (1999) was amended to include a new section (4A)

concerning the administration of health care to patients who do not have the ability to provide informed consent and to those who oppose treatment (Board of Health Supervision 2008). In our study, one patient called for caution and advised health personnel to be more responsive to patients, particularly if the treatment has elements of force.

In their study, Torheim and Gjengedal (2010) stated that mask treatment 'from the patients' point of view may be characterised as a feeling of being trapped in a situation of complete dependence on others' (p. 499) and that the lack of air leads to exhaustion, accompanied by a strong feeling of anxiety. Other studies also reported that patients experience a strong feeling of fear during an acute exacerbation (Bailey 2001, Barnett 2005). On the one hand, some patients in the present study described feeling like they were in a dreamlike condition and not understanding how serious their condition was; hence, they did not experience anxiety. On the other hand, some patients described having a level of anxiety so intense that they were unable to cooperate.

With respect to participation during the acute phase, several patients said that they did not want to participate. They realised that they needed caregivers who could act with authority. Several patients also viewed an acute exacerbation as a life or death situation. A previous study showed that intensive care nurses often experience difficulty in cooperating with patients in the acute phase because the patients become confused as a result of anxiety and hypoxia. The nurses said that they try to address patient participation in a more indirect way by reading patients' body language and by obtaining information from the next of kin (Kvangarsnes *et al.* 2013).

An important aspect of successful treatment is patients' trust in their caregivers. In their study, Torheim and Gjengedal (2010) highlighted the importance of patients having trust and a feeling of security when coping with the mask treatment. In our study, the patients repeatedly said that they trusted the health personnel during the acute phase when they needed someone to help them breathe. In this situation, there was no room for distrust. The patients commended the health personnel, especially the intensive care nurses. However, one patient thought the health personnel had gone too far in using force to administer treatment. This patient's reaction points to the vulnerability of patients in such situations and, consequently, the importance of a relationship based on trust when mask treatment is about to be administered.

When patients have a strong dependent relationship with their caregivers, it can be difficult for the patients to criticise their care. In the present study, some patients

noted deficiencies in their treatment and described being disregarded. One patient revealed that she had not dared to take a sleeping tablet during her respirator treatment because she did not trust the nurse who was supposed to look after her to ensure that she had an open respiratory passage. Another patient stated that some nurses had denied her access to her alarm (her only means of summoning help) so that they could 'get some peace'. Bailey and Tilley (2002) pointed out that nurses should view patient stories as meaning making rather than truth-telling. Several patients in the present study knew that their condition affected their experiences, but they were more interested in conveying *how* they had experienced the situation than what might be 'true'. The patients' stories also revealed that they are sensitive to the body language of doctors and nurses. Listening to patients' stories can provide a deeper understanding of the patients' lifeworld.

## Conclusion

This study shows that patients with COPD exacerbation experience that they are in a particularly vulnerable situation because their condition makes them totally dependent upon help from health personnel to be able to breathe. Patients' ability to trust caregivers in such situations is important for successful treatment. The patients in this study trusted the health personnel to help them breathe,

but told stories of distrust with regard to other aspects of their treatment.

## Relevance to clinical practice

Health personnel can learn from patients' stories to obtain insight into how the patients experience the treatment and the relationship between patient and caregiver.

During an acute exacerbation of COPD, patients should not be left alone without the means to call for help. The present study also shows that patients are sensitive to patronising attitudes exhibited by some caregivers. Health personnel should realise how they administer power during treatment of an acute exacerbation. Awareness of building a good relationship between patient and caregiver is essential in nursing in these situations.

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## References

- Act of 2 July 1999 No. 63 Relating to Patients' Rights (the Patients' Rights Act). Available at: <http://www lovdata.no/> (accessed 5 October 2010).
- Ambrosino N & Vaghegini G (2007) Non-invasive ventilation in exacerbations of COPD. *International Journal of Chronic Obstructive Pulmonary Disease* 2, 471–476.
- Andenæs R, Kalfoss MH & Wahl AK (2006) Coping and psychological distress in hospitalized patients with chronic obstructive pulmonary disease. *The Journal of Acute and Critical Care* 35, 46–57.
- Bailey PH (2001) Death stories: acute exacerbations of chronic obstructive pulmonary disease. *Qualitative Health Research* 11, 322–338.
- Bailey PH (2004) The dyspnea-anxiety-dyspnea cycle—COPD patients' stories of breathlessness: 'It's scary/when you can't breathe'. *Qualitative Health Research* 14, 760–778.
- Bailey PH & Tilley S (2002) Storytelling and the interpretation of meaning in qualitative research. *Journal of Advanced Nursing* 38, 573–583.
- Barnett M (2005) Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences. *Journal of Clinical Nursing* 14, 805–812.
- Board of Health Supervision (2008) The Patients' Rights Act Chapter 4 A. Rundskriv Helsedirektoratet.
- Chase SE (2005) Narrative inquiry: multiple lenses, approaches, voices. In *The Sage Handbook of Qualitative Research*, 3rd edn (Denzin NK & Lincoln YS eds). Sage Publication, Thousand Oaks, CA, pp. 651–679.
- Czarniawska B (2004) *Narratives in Social Science Research*. Sage, Los Angeles, CA.
- Elkington H, White P, Addington-Hall J, Higgs R & Pettinari C (2004) The last year of life of COPD: a qualitative study of symptoms and services. *Respiratory Medicine* 98, 439–445.
- Fairclough N (1992) *Discourse and Social Change*. Polity Press, Cambridge.
- Gardiner C, Gott M, Payne S, Small N, Barnes S, Halpin D, Ruse C & Seamark D (2010) Exploring the care needs of patients with advanced COPD: an overview of the literature. *Respiratory Medicine* 104, 159–165.
- Grimen H (2008) Profesjonog tillit (Profession and trust). In *Profesjonsstudier (Vocational studies)* (Molander A & Terum LI eds). Universitetsforlaget, Oslo, pp. 197–215.
- Grimen H (2009) *Hva er tillit (What is Trust?)*. Univeristetsforlaget, Oslo.
- Gysels M & Higginson IJ (2010) The experience of breathlessness: the social course of chronic obstructive



- pulmonary disease. *Journal of Pain and Symptom Management* **39**, 555–563.
- Keenan SP, Sinuff T, Cook DJ & Hill NS (2003) Which patients with acute exacerbation of chronic obstructive pulmonary disease benefit from noninvasive positive-pressure ventilation? A systematic review of the literature *Annals of Internal Medicine* **138**, 861–870.
- Kessler R, Ståhl E, Vogelmeier C, Haughney J, Trudeau E, Löfdahl CG, Partridge MR (2006) Patient understanding, detection, and experience of COPD exacerbations: an observational, interview-based study. *Chest* **130**, 133–142.
- Kvale S & Brinkmann S (2009) *Interviews: Learning the Craft of Qualitative Research Interviewing*. Sage, Los Angeles, CA.
- Kvangarsnes M, Torheim H, Hole T & Öhlund LS (2013) Intensive care unit nurses' perceptions of patient participation in the acute phase of chronic obstructive pulmonary disease exacerbation: an interview study. *Journal of Advanced Nursing* **69**, 425–434.
- Ministry of Health and Care Services (2006) *Nasjonal Strategy for COPD (2006–2011)*.
- Miravittles M, Anzueto A, Legnani D, Forstmeier L & Fargel M (2007) Patient's perception of exacerbations of COPD—the PERCEIVE study. *Respiratory Medicine* **101**, 453–460.
- Morse JM & Richards L (2002) *Read-me First for a User's Guide to Qualitative Methods*. Sage, Thousand Oaks, CA.
- Polit DF & Beck CT (2008) *Nursing Research. Generating and Assessing Evidence for Nursing Practice*, 8th edn. Lippincott Williams & Wilkins, Philadelphia, PA.
- Polkinghorne DE (1988) *Narrative Knowing and the Human Sciences*. State University of New York Press, Albany, NY.
- Terum LI (2003) *Portvakt i velferdsstaten. Om skjønn og beslutninger i sosialtjenesten (Gate-keeper of the Welfare-State. On Assessment and Decision-Making in the Social Services)*. Kommuneforlaget, Oslo.
- Theander K & Unosson M (2004) Fatigue in patients with chronic obstructive pulmonary disease. *Journal of Advanced Nursing* **45**, 172–177.
- Torheim H & Gjengedal E (2010) How to cope with the mask? Experiences of mask treatment in patients with acute chronic obstructive pulmonary disease-exacerbations. *Scandinavian Journal of Caring Sciences* **24**, 499–506.
- World Health Organization (2012) *Chronic Respiratory Diseases: Chronic Obstructive Pulmonary Disease (COPD)*. Available at: <http://www.who.int/respiratory/copd/en/on> (accessed 28 January 2012).

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