Patients’ statements and experiences concerning receiving mechanical ventilation: a prospective video-recorded study

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Prospective studies using video-recordings of patients during mechanical ventilator treatment (MVT) while conscious have not previously been published. The aim was to describe patients’ statements, communication and facial expressions during a video-recorded interview while undergoing MVT. Content analysis and hermeneutics inspired by the philosophy of Gadamer were used. The patients experienced almost constant difficulties in breathing and lost their voice. The most common types of communication techniques patients used were nodding or shaking the head. Their expressions were interpreted as stiffened facial expression, tense body position and feelings of sadness and sorrow. Nursing care for patients’ conscious during MVT is challenging as it creates new demands regarding the content of the care provided. In caring for patients undergoing MVT while conscious, establishing a caring relationship, making patients feel safe and helping them to communicate seem to be most important for alleviating discomfort and instilling hope.

Keywords: hermeneutics, mechanical ventilation, video-recording.

There is an increasing trend in European/Scandinavian countries to use light sedation regimens or no sedation at all, for patients on mechanical ventilation as soon as their condition allows. Light sedation is preferable from a medical perspective as it reduces physiological complications and immobility (Samuelsson 2006) resulting in shorter times spent in intensive care units (ICU) and hospitals compared to the situation if full sedation is used (Ström, Martinussen, and Toft 2010).

Patients’ experiences of mechanical ventilation treatment (MVT) are often associated with feelings of panic, fear and discomfort caused by the tube (Samuelsson 2006; Davies 2007; Varga, Dioszeghy, and Frituz 2007). Being unable to communicate has been reported to evoke feelings of helplessness (Bergbom-Engberg and Haljamäe 1989; Sheen and Oates 2005; Samuelsson 2006). These studies are, however, retrospective and provide no information about the patients’ immediate experiences during treatment and do not report levels of sedation or patient consciousness.

Patients are known to have difficulties in recalling what has happened after being deeply sedated and unconscious. Some patients have no memories at all of receiving MVT and/or of their time in the ICU (Löf, Berggren, and Ahlström 2006; Engström, Andersson, and Söderberg 2008). However, data are lacking concerning the patient’s immediate situation of being on a ventilator and communicating while under light sedation and thus conscious. Such knowledge about patients’ experiences of being conscious and
communicating during MVT will hopefully help nurses in ICUs to be prepared to meet these patients’ nursing care needs. Very few studies (Karlsson and Forsberg 2008) have reported patients’ experiences of being conscious and communicating during MVT.

The aim of this study was therefore to describe patients’ statements about their situation while conscious and receiving MVT, how they communicate and their facial expressions during a video-recorded interview. The following research questions guided the study: (i) What do patients report about their experiences while trying to communicate? (ii) What communication patterns do the patients use during the interviews while receiving MVT? and (iii) What facial and body expressions do patients exhibit when receiving MVT?

THEORETICAL FRAMEWORK

Morse (2001) has identified two aspects of suffering – enduring and emotional suffering. Enduring suffering can be regarded as a strategy whereby the injured/sick person can endure what he/she has to go through and in its most extreme form it makes a person appear emotionless. Eriksson’s (2006) description of a theory of suffering is another way of understanding ill/injured patients. One aspect of a person’s suffering is caused by the illness and the treatment. Unfortunately, suffering can also be caused by poor professional care, such as neglect and failure to perform caring responsibilities, which violates the patient’s dignity and human value.

Løgstrup (1992) points out that people meet each other with an open mind and naturally display mutual trust and are therefore prepared to place themselves in the hands of others if necessary. Patients who need intensive care and MVT have no choice, and they have to place themselves in the hands of the caring personnel – both literally and metaphorically. People who are healthy, or in no need of help, can choose who they want to be close to or confide in. Løgstrup (1992) argues that when a person puts himself at the mercy of another, he expects to be well received. When patients place themselves in the hands of the caregivers, they expect to be cared for and protected (Eriksson 2006).

Some interpersonal communication is in the form of facial expressions. The eyes and mouth express emotions and the face “invites others to communicate”, as well as reminding them of their obligations and responsibility for the other’s suffering, i.e. that they should act spontaneously (Kemp 1992). As verbal communication is temporarily lost when receiving MVT, body and facial expressions are the main form of communication. The relationship between patient and caregiver is asymmetrical (Kasén 2002) because the caregiver provides and the patient needs and accepts care. The caregiver thus has the responsibility, as well as the power, to ensure that the patient is provided with care.

METHOD

Both qualitative and quantitative content analyses were applied to the data from the video-recorded interviews, from patients’ statements concerning receiving MVT and how they communicated. These findings will be presented as Parts I and II, respectively in the Findings section.

A hermeneutic approach (Gadamer 1989) was used to interpret patients’ video-recorded facial expressions during the interviews. The first step in the analysis of the patients’ statements was a manifest qualitative content analysis guided by the writings of Granheim and Lundman (2004). The reason for using this approach was that the patients’ short answers were mediated in writing or by nodding or shaking the head. A quantitative content analysis was used in the second step, focusing on how the patients communicated (Krippendorff 2004). The authors registered and counted each type of communicative strategy the patients used during the recording, such as nods, gestures, writing on a sheet of paper and a type of mimicry. In the third step, a hermeneutic interpretation inspired by the writings of Gadamer (1989) was applied in analysing the patients’ appearance and facial expressions. The analysis and interpretation are based on several “readings” of the video tapes.

When starting the final step of the analysis, the authors had a new understanding based on the two previous analyses: analysis of the patients’ statements and descriptions/analysis of the types of communication strategies the patients used. This understanding, together with the theoretical foundation described in the theoretical frame of references, formed the basis for interpretation. Additionally, the researchers’ pre-understanding rests on many years’ experience of work in ICU environments and earlier encounters with patients receiving ventilator care as well as knowledge gained in previous research.

Procedure and participants

The Motor Activity Assessment Scale (MAAS) (Devlin et al. 1999) was employed in the study to assess the patients’ level of sedation. This scale has been tested for validity and reliability (De Jonghe et al. 2000). Level 0 indicates no reaction, while level 6 indicates an anxious and/or agitated patient. MAAS 3 means that the patient is sedated but calm and cooperative. The study inclusion criteria were as follows:
MAAS score of 3–4 for at least 18 hours during their time on
the ventilator, aged 18 years or over, and able to speak and
understand Swedish. Moreover, it had to be clearly docu-
mented in the medical record that the patient was able do
one of following: sit on the bedside, read books, write using
pencil and paper, mouth/mime or shake their heads. Fifteen
patients were invited to participate in the study, one patient
declined. The participants comprised four women and ten
men aged 23–88 years (mean age 57). Data such as diagnosis
resulting in MVT are presented in table 1. The video-
recorded interviews were conducted between day 2 and day
14 after arrival in the ICU.

The potential participants were provided with written
and oral information about the study, and asked by their
allocated nurse if they would like to join. The first author
chose suitable patients in consultation with the nurses
involved and in accordance with the inclusion criteria, after
which the patient’s nurse invited the patient to participate in
the study. Patients who consented were contacted by the first
author, and once again given information about the study
and asked about their willingness to participate. If they
agreed, informed written consent was obtained. The particip-
ants were given extra time to consider their decision to take
part, and the information was repeated twice to enable them
to consider their informed consent thoroughly. ICU patients
are considered a vulnerable group, and the researcher there-
fore took extra precautions regarding the video-recording
procedure. The camera’s presence was not hidden (Angro-
sino 2007), and the participants could comment on the cam-
era’s position. The participants also knew that no one except
the actual researchers had access to the tapes during the pro-
cess of analysis. Since publication, the films have been kept
in a special safe deposit box at the university, in accordance
with Swedish law governing protection of research data.

Noise and sound as well as conversations between another
patient and nurses in the same room were captured on the

<p>| Table 1  Patient data, describing diagnosis, length of stay in the intensive care units, tube/cannula and sedation during interview |
|---------------------------------|---------------------------------|---------------------------------|</p>
<table>
<thead>
<tr>
<th>Diagnosis (age in years), LOS in days</th>
<th>Tube/Tracheotomy/ventilator/probe</th>
<th>Sedation or analgesic during interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epiglottitis, throat abscess (61), 12 days</td>
<td>Tracheotomy, ventilator</td>
<td>Fentanyl 50 μg/ml, 1.9 ml/hours</td>
</tr>
<tr>
<td>Stroke (56), 8 days</td>
<td>Oral endotracheal tube, ventilator, probe</td>
<td>No</td>
</tr>
<tr>
<td>Myelitis (37), 6 days</td>
<td>Oral endotracheal tube, ventilator, probe</td>
<td>No</td>
</tr>
<tr>
<td>Epiglottitis (63), 2.5 days</td>
<td>Nasal tube, HME, sb</td>
<td>No</td>
</tr>
<tr>
<td>Difficult to intubate in conjunction with surgery (79), 2 days</td>
<td>Tracheotomy, HME, sb</td>
<td>No</td>
</tr>
<tr>
<td>Larynx cancer (59), 2 days</td>
<td>Tracheotomy, HME, sb</td>
<td>No</td>
</tr>
<tr>
<td>Multiple-trauma (23), 9 days</td>
<td>Oral tube, ventilator</td>
<td>Propofol 20 mg/ml, 4 ml/hours. Fentanyl 50 μg/ml, 1 ml/hours</td>
</tr>
<tr>
<td>Carotid surgery (69), 10 days</td>
<td>Tracheotomy, ventilator, probe</td>
<td>Morphine® 1 mg/ml, 2 mg at 07.30, about 30 minutes before interview</td>
</tr>
<tr>
<td>Carotid surgery (88), 5 days</td>
<td>Oral tube, ventilator, probe</td>
<td>No</td>
</tr>
<tr>
<td>Airway obstruction (65), 4 days</td>
<td>Nasal tube, ventilator</td>
<td>No</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease (COPD; 61), 15 days</td>
<td>Tracheotomy, ventilator, probe</td>
<td>No</td>
</tr>
<tr>
<td>Myasthenia gravis crisis (87), 6 days</td>
<td>Nasal tube, ventilator, probe</td>
<td>Fentanyl 50 μg/ml, 5 ml/hours. Bolus Fentanyl 50 μg/ml, 1 ml at 13.00. Clonidin 15 μg/ml, 4 ml/hours</td>
</tr>
<tr>
<td>Multiple-trauma (42), 4 days</td>
<td>Tracheotomy, HME, sb</td>
<td>Propofol 20 mg/ml, 6 ml/hours and Clonidin 15 μg/ml, 10 ml/hours</td>
</tr>
<tr>
<td>Sepsis, pneumonia, pneumothorax (24), 23 days</td>
<td>Tracheotomy, ventilator, thorax drainage, probe</td>
<td></td>
</tr>
</tbody>
</table>

HME: heat and moisture exchange; sb: spontaneous breathing.
tape, but these conversations were not transcribed into text, being regarded as background noise.

**Setting**

The study was carried out in a county hospital in Sweden with a general, 8-bed ICU, which cares for both children and adults. In 2008, a total of 789 patients were cared for at the unit and of these, 419 received invasive MVT. The video-recordings were carried out in the patients’ rooms with staff present. The care procedures for the other patients in the room continued during the video-recording and interview.

**Data collection**

Each patient’s communicative techniques were observed for an hour prior to the interview, so that the interviewer would be able to understand the patient/participant more quickly. The interview guide is shown in Box 1.

The interview guide was made beforehand and based on previous research literature. The number of questions in the guide might be considered too many for interviews with seriously ill patients. The interviewer was therefore prepared to interrupt the interview if the patient seemed to be exhausted. However, all patients were able to answer all questions. The opening question worked as an introduction to the interview situation and aimed to initiate the conversation. Overall, the patients answered these questions briefly. Questions were asked in such a way that it was easy for the patient to answer in a few words, or with a nod or shake of the head. Where the participant answered questions in writing, the researcher read the answers back to the patient, so that statements were recorded and confirmed. Oral but silent answers were repeated aloud by the interviewer for the recording and to give the patient the opportunity to confirm them. The video camera was placed in front of the participant, beside the bed, so that facial expressions were visible. Gestures were sometimes out of camera shot as the participants often held a sheet of paper they could write on. The interviewer sat beside the bed and could see what the participants were writing as well as their hands, face, eyes and body positions. The video interviews lasted about 5–16 minutes each (mean time 10 minutes) and were transcribed immediately after they had taken place. The ambition was to keep the interviews short as the patients’ condition made longer interviews impossible. Data collection began at the end of January 2008 and continued until February 2009.

**Ethical considerations**

This study was approved by the university’s Research Ethics Committee (Dnr 552-07). All patients were conscious and undergoing MVT when they were asked about participation by their nurse and received information verbally and in writing. Information about informed consent was given according to the Helsinki Declaration (World Medical Association 2008) regarding autonomy, beneficence, justice and nonmaleficence. The interviewer (VK) decided with the participants the best time of day for the interview, as she did not want to interrupt rest and sleep or activities/procedures involving the participant. In this way, the participants controlled the research process and the interviewer assumed the role of a guest visiting the participant (Clarke 2006).

The participants were all in a vulnerable and dependent situation, and there was a risk that they would feel forced to participate in the study. Patients were informed that they could choose to end the interview at any time without giving any reason and without prejudice, and the interviewer was careful not

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**Box 1  Interview guide**

1. Can you describe what it is like to be awake during your ventilator treatment?
2. Have you been able to communicate in the time you have been awake during your ventilator treatment?
3. What makes you feel good when you are awake during your ventilator treatment (security, communication)?
4. What is “hard” for you when you are awake during your ventilator treatment (suctioning airways, pain)?
5. Have you had nightmares during your ventilator treatment?
6. Have you been able to relax and sleep during your ventilator treatment?
7. Have you been visited by relatives while you were awake during your ventilator treatment? What did it feel like having visits from relatives? What was it like talking to (communicating with) your relatives?
8. What is it like getting out of bed when you are awake during your ventilator treatment (sitting on the edge of the bed, in an easy chair, wheel chair, tip board)?
9. Do you long for something when you are awake during your ventilator treatment (food, drink, tastes, smells, long for home)?

Examples of follow-up questions: Would you like to tell me more about that? Would you like to explain?
to pressure them in any way. The interviewer met the participants again for a follow-up interview after they had left the ICU. They were asked to describe their experience and recollection of being video-taped. All participants remembered being video-filmed and none reported any problems. The interviewer did not play an active role in the patients’ caring process, and the patients had no caring relationship with the researcher. However, the risk remains of a power imbalance between the interviewer and participant (Hewitt 2007). One interview was interrupted when the interviewer noticed that the participant had no energy left, asked if they wanted to end the interview, the participant confirmed that he/she did.

Interpretation and analysis

The interviews were video-recorded and transcribed verbatim by the first author. Each transcribed interview was read several times by all authors to familiarise themselves with the overall content and the patients’ statements about their situation. The text was considered to be short but rich in content. The text was then read sentence by sentence to identify meaning units (Graneheim and Lundman 2004), first in each individual interview and then in all interviews. A meaning unit could be a constellation of statements or words that relate to the same meaning (Graneheim and Lundman 2004). The content of each interview was then compared across all interviews, and meaning units were identified and categorised. All the authors discussed the results of the analysis to reach a consensus. Quotations were used to validate the analysis of the interview text.

Following the first step in the analysis of the interviews, each video-recording was viewed several times by all the authors to identify how patients communicated and what forms of communication they used during the interview. Patients’ different ways of communicating, such as writing, facial expressions, nods or headshakes, mouthing and gestures, were noted, and an individual pattern for each patient was identified. The number of patients who used the same type of communication was noted.

In the third step, each author watched the videotapes again several times and wrote down their impression of the patients’ facial expressions as well as their own individual interpretations and understanding. The interpretations of the videotapes were based on the question, “What is this about?” (Gadamer 1989). The authors then compared what they had seen until all aspects had been elucidated.

FINDINGS

The findings are reported in three parts. The first part comprises patients’ reports of experiences during MVT; the second part describes patients’ communication patterns when they “talked” with the interviewer during MVT; the third part presents an interpretation of what patients communicate through their facial expressions during MVT. When listening to the tapes, we noticed that there were many sounds from apparatus, telephones and monitoring equipment, generated both around other patients’ beds and by the patients participating in this study. On several tapes, the voices of caregivers busy with various procedures involving other patients in the room could be heard and even voices from (other) neighbouring patients.

Part I: Patients’ reports of their experiences during mechanical ventilation

In the first part, a qualitative content analysis concerning the patients’ speech was used to report on the patients’ situation, when receiving MVT. Six categories were identified.

THE TUBE AND TRACHEOTOMY CAUSED PAIN, DISCOMFORT AND BREATHING DIFFICULTIES

Not getting any or insufficient air was experienced as being in hell. It was connected with a feeling of being suffocated and evoked panic, “It’s hell. Not getting air” (1). Patients said that it was difficult to get air when they had to move, but after sitting on a chair or the edge of the bed for a while, this feeling disappeared. One of the patients said “Yes, it feels good getting out of bed, easier to breathe after a while” (4). One of the patients felt that having a tracheotomy was better than being intubated. Being intubated was difficult because they felt unable to control their own breathing. The tube and nasogastric tube were irritating and caused pain and nausea. The tube felt like something big and horrible in the throat. “The tube in my mouth and the probe in my nose hurt” (3).

The patients also found it difficult to breathe through the endotracheal tube or tracheal cannula and sometimes felt they had to constantly think about breathing. Not getting enough air also made it difficult for them to sleep as they were unable to relax.

SUCTION PROCEDURE CAUSED PANIC BUT ALSO RELIEF

Secretion in the airways was suffocating, and suctioning to remove it brought relief. However, suction was also reported to cause feelings of panic, especially if the nurse was heavy-handed and inserted the suction tube too deeply into the trachea. “It’s really awful then when they pushed the suction tube too far down. Panicked” (6). Some patients preferred to do the suctioning themselves as they knew where the secretion was and how deep down they could insert the tube. “Good to do the suctioning oneself in one’s mouth; know
where the phlegm is, difficult because they push too deep in one’s mouth. Know myself how far down to go’ (10). The suction of secretion was also reported as a procedure that interrupted sleep.

THE TUBE TOOK AWAY THE VOICE AND MADE COMMUNICATING STRANGE

Not being able to talk and having no voice was troublesome, discomfiting and strange for some, creating communication problems. Others felt secure in the belief that they were understood by the professionals. Writing to make themselves understood by both nurses and relatives, took all their energy and was regarded as very taxing. One of the patients said: “Writing is really tough, it takes all one’s energy. Am afraid of forgetting to breathe while I’m writing” (7). One of the participants felt that it was easier to communicate once he had his tracheostomy and did not feel as shut off (as with an endotracheal tube) “Felt cut off with the tube, couldn’t see and be seen in the same way” (6). The patients liked visits from relatives/close friends, but some found it difficult because they were unable to convey what they wanted to communicate.

THE PRESENCE OF RELATIVES AND NURSES EVOKED FEELINGS OF SECURITY AND WELL-BEING

Patients’ reported that it was difficult to feel well, but they felt cared for by the nurses especially when they were sharing jokes with them. They also reported being taken care of by the nurses (and that the nurses cared for them) in every way, which made them feel safe and secure, allowing them to relax and sleep. The patients really appreciated feeling that the caregivers understood their attempts to communicate; this simplified matters and increased their sense of well-being.

HOPE AND LONGING TO BE HEALTHY AND RETURN TO A NORMAL LIFE

Homesickness seemed to keep hope alive. Regaining strength led some patients to feel well and believe in recovery. Longing for health and a normal life again made them feel well. The patients learned to get rid of the tube and return home to their family, and in some cases, they longed for their pets. Relatives’ visits were also considered important and contributed to feelings of security.

Six of the patients said that they had a dry mouth and were thirsty. They longed for something tasty to drink, such as coffee, tea with honey, beer or raspberry soda. One patient said: “Home and tea with honey” (1). Six of the patients had managed to sit on the edge of their bed or a chair, one had even gone to the toilet, which resulted in them daring to hope to regain a “normal life” (8). Some said that nothing could help them feel well while they were intubated or had a tracheotomy, as the tube usually caused pain and discomfort.

NOT BEING ABLE TO SLEEP AND REST

The patients usually found it difficult to sleep, they could only sleep one or two hours at a time or were unable to sleep and relax at all, making them feel exhausted. Being unable to sleep was regarded as an obstacle to regaining one’s health. “A bit difficult to sleep, rest a bit but not really properly, difficult to relax – discomfort in my throat and not getting air – feeling of panic” (8). They were disturbed and awakened by staff or other patients or the noise of machines and equipment. The nights were experienced as long and boring, but watching TV made them easier. Patients stated that they sometimes had bad dreams, which made them feel uncomfortable and afraid of falling asleep, “dreaming about nasty things” (3). Four of the patients had had nightmares or peculiar dreams, but they were unable to talk about them because this would have required too many words. However, five of them said that sleeping was not a problem.

Part II: Patients’ communication patterns during the interview

In the second part, quantitative content analysis was used to describe patients’ communication patterns during the interviews. The patients developed individual styles of communication while on the ventilator, but there were common characteristics (table 2).

Most of the patients used aids such as pen and paper, although some were unable to write because of injuries caused by trauma or disease or because their hands were too

Table 2  Description of various communication techniques used during the interviews. The same patient may have used several techniques

<table>
<thead>
<tr>
<th>Description</th>
<th>Techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facial expression</td>
<td>Gestures with arms, hands and fingers</td>
</tr>
<tr>
<td>Winks, $n = 12$</td>
<td>Gesticulates, $n = 9$</td>
</tr>
<tr>
<td>Raises eyebrows, $n = 8$</td>
<td>Throws out arms/ hands, $n = 3$</td>
</tr>
<tr>
<td>Shuts eyes, $n = 1$</td>
<td>Raises hand to show stop, $n = 1$</td>
</tr>
<tr>
<td>Wrinkles forehead, $n = 7$</td>
<td>Thumbs up, $n = 2$</td>
</tr>
<tr>
<td>Knits eyebrows, $n = 5$</td>
<td>Points, $n = 8$</td>
</tr>
<tr>
<td>Make a face, $n = 3$</td>
<td>Points/shows with fingers, $n = 2$</td>
</tr>
<tr>
<td>Mimes (forms words with lips), $n = 9$</td>
<td>Shrugs shoulders, $n = 2$</td>
</tr>
<tr>
<td>Expressionless, $n = 4$</td>
<td>Pats chest, $n = 1$</td>
</tr>
</tbody>
</table>
shaky. The patients’ handwriting varied, sometimes the text was difficult to read – the sentences ran into each other and the letters were sometimes written on top of one another – making it difficult to decipher their responses to the interviewer’s questions. In such cases, the interviewer repeated the question and sometimes the patients rewrote the answer or the interviewer asked additional questions, so that they could nod, shake their heads or answer the question in some other way. When the interviewer read incorrectly or misunderstood, the participants revised the content; some clearly showed their irritation while others were patient and repeated the answer with a tired and understanding smile. The patients gesticulated when they wanted something or to answer, they used their fingers to show a figure. One of the patients made a stop sign with his hand when the interviewer interpreted the answer too quickly and the patient had more to say. Another patient gave the thumbs-up signal when the interviewer correctly interpreted the answer. The participants used facial expressions to varying extents. Some frowned and raised their eyebrows, but many did not use facial expressions. Four patients smiled briefly during the interview, one started to cry. Only one of the four patients with an oral endotracheal tube mouthed his answers during the interview. Three who were nasally intubated mouthed some of their answers. All the patients nodded and shook their head, except for two who blinked.

**Part III: Facial expressions and a tense body position**

The third part of the results consists of the interpretations of the patients’ countenance and body position during the videotaped interviews using a hermeneutic approach. The overall interpretation was summarised in three themes.

**A STIFF FACIAL EXPRESSION**

The patients are “tied” to their beds by medical equipment such as ventilator tubes, a gastric tube for enteral nutrition, ECG electrodes, oxygen saturation measurements/oxygen saturation probe, lines for infusions and/or for medication pumps, an arterial blood monitor system and, for some, drainage tubes on the side of their neck.

Nasal, oral and tracheal tubes and various probes made the patients’ faces look strange; most of them were swollen and covered with tapes/plasters, which seemed to transform them into “nonpeople”, without personality. In some cases, as the patient’s mouth could not be seen, their ability to use their face to communicate was limited. The patients’ faces showed little expression and were lifeless. Several partici-

pents did not make eye contact, with the interviewer or look into the video camera at all.

**A TENSE BODY POSITION**

The patients’ recumbent bodies looked tense, and they turned their heads slowly when looking around the room regardless of whether they had an endotracheal tube or tracheotomy. The overall impression was that the patients all lay on their backs at strict attention, unable to relax except for one who sat up during the interview. They moved their head carefully and pushed it back against the pillow. Some lay completely still in bed, some used their arms and hands only occasionally, while others tried to change the position of their body or adjust the position of the gastric probe and ventilator tubes. The patients’ heads were usually turned towards the ventilator; they were unable to turn their head in the other direction because that would stretch the ventilator tubes. To the researchers, this looked like a locked position. One patient placed his right arm above his head on the pillow for short periods, another carefully adjusted the blanket with his finger, to which was attached equipment for measuring oxygen saturation, yet another moved his upper body and head sideways, and leaned forwards a little. All movements were made very carefully. Several patients lay completely still, arms against their sides as if standing to attention or their hands lay motionless on their midriff/chest. They were possibly afraid of causing trouble for themselves and the staff because of the number of lines and connections to the equipment which were enabling them to survive. They moved as little as they could to spare themselves and just waited to get “better”/make progress. This tense body position could also be interpreted to mean the patients were holding themselves and their body together (enduring) to avoid panicking, while waiting for the situation to come to an end.

Lying in bed is interpreted as affecting people because it implies being in a very private or intimate situation. Normally, people meet each other sitting or standing. The patients wear only a hospital gown, and some open down to the chest (unbuttoned) others hardly buttoned at all. Lying in bed half-dressed with uncombed hair affects people when they meet others they do not know (caregivers, doctors) while in one of life’s most difficult situations.

**BEING SAD AND SORROWFUL**

The patients’ gazes expressed sadness and sorrow while their facial expressions seemed to be lifeless and expressionless. The gaze mediated from most of the patients seemed to be silent and empty. Some of them had their eyes just open or
sometimes completely closed during the interview – their gaze and eyes seemed tired, exhausted and their eyelids heavy. Many of the patients showed an introverted attitude and seemed to be resigned; for example, when they answered the interview question, they averted their eyes and their gaze faded or disappeared. It was difficult to maintain eye contact although some made contact now and then with the interviewer. These patients had a lively look in their eyes compared to the others, as if they were trying to maintain and display their normal self. They also had a more open look and appeared less exhausted. The overall interpretation is that patients had a lifeless gaze and seemed to have withdrawn into themselves (from real life). This gaze permeated all the findings and affected the authors emotionally. Even though some patients sometimes joked during the interview, the overall impression was one of sadness and sorrow.

**INTERPRETATION**

We used Morse’s (2001) theory concerning suffering with respect to how patients express enduring and emotional suffering, and Løgstrup’s (1992) theory about trust between human beings as a frame for the interpretation. Lévinas’ ideas (Kemp 1992) were also used in this step of the analysis to acquire a deeper understanding of the meanings the participants mediated via their gaze and facial expression.

When Morse (2001) describes enduring in patients who are suffering from an illness, their faces are stiff and expressionless and their mouth movements are small; their eyes do not move and are unfocused; when they look around the room, their eyes move mechanically, robot-like and they seldom blink (Morse 2001). In this study, it was found that the patients’ faces were stiff and lifeless and all their movements were slow, which is in line with Morse’s (2001) descriptions of enduring. They nodded and shook their head very carefully. Connections, wires and lines to equipment created a feeling of being imprisoned, leading to a stiff body position. However, the stiff body position could also have been an expression of suffering, of being in a situation that was “too much”, which had to be enclosed within the body in order for them to manage existence.

According to Gadamer (1996), the body represents life and the soul is seen as life giving, and the body and soul are reflected in each other. Facial expression, gaze and body appearance can be seen as embodiments of this reflection. The patients’ averted eyes communicated sadness and withdrawal. We interpreted a lifeless look and a frozen appearance as signs of unbearable suffering. This is a call to the other (Kemp 1992) and a call for responsibility to be taken care of and suffering to be alleviated (Eriksson 2006). According to Lévinas (Kemp 1992), the face is important in contact with others; it is the face that invites participation and reminds the caregivers of their obligations. A patients’ appearance changes in serious illness, the face is swollen, hidden by plasters and tubes and the question is how this affects encounters between people.

There is a risk that the caregivers interpret this appearance as meaning that the patient does not want to be disturbed or contacted. The lack of a frame of reference, about what the patient looked like when healthy and without plasters (tape to fix the tube) and tubes, also makes it difficult to interpret their facial expression. Patients seem not to want contact, their facial expressions are not directed towards others but indicate withdrawal.

As in more “everyday” contexts, the look in a person’s eyes speaks and appeals to the other person’s responsibility (Kemp 1992), attempts by the caregivers to catch their eye when the patient is keeping his eyes averted could be construed as trespassing. According to Gadamer (1996), people become preoccupied with, and to some extent locked inside, themselves when in bad health and suffering and thus are unprepared to meet other people concerning their needs. Our interpretation is that the patients in the present study were incapable of being (outwardly) oriented to the outer world or open to others; instead, their ill-being absorbed all their attention. Gadamer (1996) argues that in severe illness, the body becomes a protective covering and acts as a defence.

**DISCUSSION**

**Reflections and critique of methods**

The interviews had to be performed quickly (average 10 minutes), which was judged to be reasonable considering the patients’ severe condition. The interviewer had to be very concentrated and ask relevant questions which could easily be answered in a few words, risking superficiality. It is debatable whether it is, ethically, advisable to video-record patients in such a situation. However, it can also be argued that in this situation, the most important messages were mediated as the patients were authentically living their medical condition, feelings and emotions at the time of the interviews. Patients were conscious while being video-recorded and interviewed and thus able to mediate/communicate their feelings in the ongoing situation. This is important for improving the care of these patients.

Interviews and video-recordings can be seen as two types of data collection. The advantage of combining them was that the interviews could be both read (as a text) and watched repeatedly, making it possible to check what had been apprehended and interpreted. This filming may possi-
ibly have inhibited the patients from communicating what they really wanted to communicate (Peräkylä 2004), but even if the interviewer had used only a tape recorder to record the interview, that problem would still exist. Similarly, the patients could have felt inhibited by the constant presence of a caregiver in the room while the interview was conducted, as they were in a state of dependence on the caregivers. However, it would have been impossible to carry out the interviews without a caregiver present, as the patients sometimes needed airway suction.

There is an increasing trend in the Scandinavian countries to apply a more restrictive sedation therapy in intensive care, which means that some ICUs have applied a regime of light doses of sedatives (Samuelsson 2006; Strom, Martinussen, and Toft 2010). The results may have been different if more patients from several ICUs had been included in the study, but at the time of this data collection, few ICUs applied this regime. It is important in future research to conduct multicentre studies from a patient perspective as conscious patients demand a different type of attention from the nurses. The ambition in this article focused on including patients who differed regarding gender, age, disease, days on MVT and length of stay in the ICU, to obtain descriptions and experiences that were as varied as possible.

Validity when using content analysis is demonstrated by careful performance and description of the research process and the descriptions and interpretations made (Krippendorff 2004). In this article, we have included quotations to demonstrate the link between data and results (Graneheim and Lundman 2004).

Our findings can be applied to other patients in an ICU who have breathing difficulties and find it hard to communicate. However, caution must be observed as each patient’s situation and preferences must be considered. A text can be interpreted using various methods, but manifest content analysis was chosen as the answers in the interviews, although short, were rich in content and described the patients’ situation well. The interviews were followed up (Silverman 2006) after the patients had left the ICU.

One of the advantages of the video-recordings was being able to re-watch them. This possibly allowed “phenomena” to be discovered that had been missed the first time but had still created a feeling that was worrying to the researchers. In interpreting the videos, the authors made use of their pre-understanding, knowledge and experience from intensive care as well as Lévinas’ (Kemp 1992), and Gadamer’s (1996) ideas about encounters and suffering (Eriksson 1992). The interpretation process moved from whole to parts to a new and greater whole as in the hermeneutic circle (Gadamer 1989). We endeavoured to adopt an open approach to what we saw in the video films, mindful of the importance of trying to balance our pre-understanding and comprehend the recordings in a variety of ways.

Reflections on the findings

Patients’ descriptions of feelings of panic, anxiety, fear, pain and discomfort caused by a tracheal tube, as well as the discomfort related to the inability to speak and communicate, are in line with those reported in previous studies (Bergbom-Engberg and Haljamäe 1989; Richman 2000; Samuelsson 2006; Ringdal, Plos, and Bergbom 2008). This knowledge has been available for many years, but it seems that patients today still report these discomforts. One reason could be that the MVT is not properly adjusted to the patient’s ventilation needs. The caregivers may also fail to provide security or a feeling of being in safe hands. This can occur for example, if the patient is experiencing increased secretions in their airways, possibly causing feelings of nausea and pain in the throat, or if they are neglected or if the staff fail to alleviate such discomforts.

Furthermore, the patient’s fear/feeling of not being in control, being totally dependent on others, could be reduced by teaching them how to communicate, move and behave in relation to the equipment used. Perhaps the nurses’ and physicians’ communication and documentation about the patient should also routinely include signs or expressions of the patient’s experience of the tube and ventilator adjustment. Another aspect that could be discussed is the need to develop tubes and other technical equipment to make them less discomforting.

In the present study, it was found that suctioning secretion caused pain and feelings of panic, especially when the suction line was inserted deeply, and in a study by Foster (2010) even suctioning in the tracheotomy was experienced as painful. Patients who are conscious are often able to suction oral mucous themselves and in a more comfortable and sensitive manner. The nurses could invite patients to participate in this more actively (Varga, Dioszeghy, and Frituz 2007). Establishing a trusting relationship through increasing the technical skills and competence of nurses seems crucial if discomfort and pain are to be avoided.

In this article, patients described their feelings of having no voice as strange. Several retrospective studies have shown that the worst thing for patients during their time in the ICU was being unable to speak (Happ et al.’s 2004; Davies 2007; Schou and Egerod 2008; Foster 2010) as this made them feel vulnerable. Our findings show that being able to communicate more effectively gave patients a feeling of power and control.
Schou and Egerod (2008) discuss caregivers helping relatives to establish a functioning communication system with the patient, as they can be a lifeline to “normal life”. In Lindahl, Sandman, and Rasmussen (2003) study, thinking of home and being home improved well-being. This was also evident in our study. The patients felt secure and safe when relatives were present even if it was sometimes difficult for them to communicate and it increased their longing for home.

COMMUNICATION AND FACIAL EXPRESSIONS

Our findings describe patients’ various communication techniques and are in agreement with Happ et al. (2004) study, in that the most commonly used are head nods, writing and lip-reading. Ashworth (1981) describes how patients communicated using small body movements two winks for “no” and one wink for “yes”. This was also seen in our study, patients blinked when the interviewer understood their answers.

It can be difficult for the staff to understand patients they have never cared for before as each has their own way of communicating. This can result in frustration and fear of failure among nurses, influencing their communication with patients (Bergbom-Engberg and Haljamae 1993). In our study, however, patients felt they were often understood when they tried to communicate with the staff. Asking questions which can be answered with yes or no is a technique that could be taught to new staff and visiting relatives. Meijers and Gustafsson (2008) found that it is easier for nurses in ICUs to neglect the patient’s wishes when they were on MVT than in other settings. This can result in patients giving up communication and withdrawing from contacts.

It takes time to establish good communication between patient and nurse, and it is important to note how patients communicate (Börsig and Steinacker 1982). It is taxing to communicate with nurses and relatives and meet new nurses in the patient’s exposed situation, and this contributes to the theme we have interpreted in the third part of the results. It is of the utmost importance for both patients and nurses that continuity of care is provided by building up and establishing good communication.

Several studies (Chanques et al. 2009; Arif-Rahu and Grap 2010; Voepel-Lewis et al. 2010) describe seriously ill patients’ facial expressions and their body language in conjunction with pain and the measurement of pain using scales (McKinley et al. 2004; Gustad, Chaboyer, and Wallis 2005). In a study by Gelinas, Fillion, and Puntillo (2008), health professionals say that facial expressions are the most reliable signs of reactions in patients who are in pain and are unable to communicate verbally. It is conceivable that what we saw and interpreted in the patients who were awake and recorded during MVT are signs of pain from an endotracheal tube and/or their illness per se, but we argue that we saw not only physical pain but also the patients enduring their suffering. This suffering is characterised by the discomfort and worry they constantly feel because of want of air, the discomfort of suction in the airways and being “tied” to medical equipment; the plasters on the face holding the tube in position also contribute to a stiff expression.

The patients’ facial expressions showing sadness and their stiff posture can be interpreted as meaning that they want to be left in peace, as if they are in a crisis situation and are protecting themselves. In this situation, the professional caregivers have to establish their presence and caring mission, showing that their interest is in the patient and that they are keeping their promise to do their utmost for them. Even if the patient seems to withdraw from contact with the nurse, the nurse should in some way demand that they are present and in contact. As patients are conscious, the nurses can talk with them and establish a contact and a trusting relationship. Nurses can also ask how and what the patient feels or experiences or the nurse can see/read in a patient’s gaze, facial expressions and body position if they are comfortable or not in the situation. Patients can also confirm if the nurse has apprehended this correctly. That is, of course, impossible when patients are sedated. Our findings may hopefully contribute to and influence nursing practice in terms of making ICU nurses more sensitive to patients’ various ways of striving to communicate. Moreover, those patients who seem to keep back or withhold communication need to be given more attention. In such cases, the facial/bodily expression could serve as a guide.

CONCLUSION

The patients who were awake during MVT experienced lack of air, pain caused by the endotracheal tube and discomfort during suctioning. They often developed their own individual communication patterns, but some techniques could easily be taught, so that relatives and patients could communicate. It therefore seems important to establish a caring and well-functioning relationship including communication and that the same caregiver continues to care for the patient.

The sorrow and sadness communicated via facial expressions, gaze and tense body position are interpreted as messages to the caregivers to protect and help the patient. The nurses’ continuous presence should mediate their promise to do their utmost but should also create a feeling that they, the patient and the relatives are a team. This, of course,
should be accompanied by adequate pain relief, the patient’s participation and the presence of relatives. In this way, the experience of being awake during MVT can probably be made endurable.

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