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Experiences of critically ill patients in the ICU

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KEYWORDS

Patient's experiences;
Intensive care;
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Summary

Background: Experiences of critically ill patients are an important aspect of the quality of care in the intensive care (ICU).

Objective: The aims of the study were firstly, to evaluate the perceptions of patients regarding nursing care in the ICU, and secondly, to explore patients' perceptions and experiences of ICU stay.

Method: A qualitative approach using a semi-structured focused interview in 11 patients was used (phase 1), followed by a quantitative approach using a self-reported questionnaire in 100 patients, 62 were returned and 50 could be evaluated (phase 2).

Results: A number of themes emerged from the interviews (phase 1), although support dominated as an important key theme. This was experienced as a continuum from the feeling being supported by the nurse to not being supported. This key theme was central to each of the three categories emerging from the data pertaining to: (1) providing the seriously ill patient with information and explanation, (2) placing the patient in a central position and (3) personal approach by the nurse. The responders to the subsequent questionnaire (phase 2) predominantly experienced sleeping disorders (48%), mostly related to the presence of noise (54%). Psychological problems after ICU stay were reported by 11% of the patients, i.e. fear, inability to concentrate, complaints of depression and hallucinations.

Conclusions: Although the nurses' expertise and technical skills are considered important, caring behaviour, relieving the patient of fear and worries were experienced as most valuable in bedside critical care.

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Introduction

Experiences of critically ill patients are an important aspect of the quality of care in the intensive care unit (ICU) and a consistent theme in research findings from 1970 to 2007 (Johnson, 1972; Asbury, 1985; Burfitt et al., 1993; Russell, 1999; McCabe, 2004; Magnus and Turkington, 2006). The goal of intensive care is not only to save lives, but also to support patients and their relatives during critical illness (Pattison, 2005). Intensive care stay may have implications for the patients' psychological well-being, both in the ICU, but also after ICU discharge (Pattison, 2005). The current treatment preference for patients requiring mechanical ventilation is to use minimal sedation levels whenever feasible (Wojnicki-Johansson, 2001). Due to this regime with a decreasing prescription of sedatives and the use of a daily wake-up call when sedated, memories of patients' experiences in the ICU are increasing. Stein-Parbury and McKinley (2000) reviewed 26 studies that used either qualitative or quantitative approaches to examine patients' experiences (Stein-Parbury and McKinley, 2000). Of the reviewed papers many patients recalled their time in the ICU, sometimes in vivid details (Bergbom-Engberg et al., 1988a). Patients recalled not only experiences that were negative but also ones that were neutral and even positive. Positive experiences included a sense of safety and security promoted especially by nurses (Burfitt et al., 1993; Holland et al., 1997). Negative experiences included impaired cognitive functioning and discomforts such as problems with sleeping, pain and anxiety (Turner et al., 1990; Holland et al., 1997). In a study of Russell (1999) some actions of ICU staff were not only remembered by ICU patients and their families but also continued to affect patients 6 months after their ICU discharge (Russell, 1999). Patients' memories of the ventilation period are especially related to the difficulty in accepting an inability to speak. Communication between patient and nurse is important. Consequently, impaired communication possibilities are related to feelings of anger and low mood, which may lead to a disturbed rehabilitation process (Magnus and Turkington, 2006). Both verbal and non-verbal communications have a major impact on the patient's emotional stability and perceived care (Rundell, 1991; Albarran, 1992; Wojnicki-Johansson, 2001; McCabe, 2004). Memories of hallucinations are a source of discomfort recalled by patients even after discharge. These experiences, also known as delusional memories, can be a sign of the so called ICU syndrome/delirium, that is a predictor of mor-

tality (Ely et al., 2004). Furthermore, delusional memories may be related to the development of post traumatic stress disorder (PTSD) (Jones et al., 2001). Nursing care for patients while in the ICU can have a positive effect on psychological well-being (Pattison, 2005). In a study of Granberg et al. interviewing 19 patients who had been ventilated, the caring relationship was perceived as the provision of an important degree of security and comfort. Nursing actions can therefore be seen as vital factors in patients overcoming ICU experiences (Granberg et al., 1998). In a study evaluating factual memories 2 years after ICU discharge, the need for continued patient information, re-assurance and optimised comfort was stressed (Roberts et al., 2007). However, exploration of the experiences of critically ill patients in the Netherlands is limited. Therefore, we decided to conduct a study exploring patient experiences during ICU stay with specific attention to the perceptions of patients regarding nursing care, support and psychological problems.

The aims of our study were twofold: firstly, to evaluate the perceptions of patients regarding nursing care in the ICU, and secondly, to explore patients' perceptions and experiences and possible psychological problems related to ICU stay.

Patients and methods

This study was part of a larger investigation examining the experiences of ICU patients. Patients admitted to the ICU (medical or surgical) of the Gelre Hospitals (Lukas site, Apeldoorn, The Netherlands) staying >48 h were selected in a 6-month period. The local ethics committee approved the study. The study was conducted in two phases. A qualitative approach using a semi-structured focused interview with a list of topics (phase 1), followed by a quantitative approach using a self-reported questionnaire (phase 2). This combined approach was chosen because we expected that this could increase our understanding about the emotional and psychological phenomena that influence patients' experiences. Disorientation was measured by checking the presence or absence of delirium in the patients. This was assessed by asking the opinions of the nurses, doctors and especially close relatives. Patients suspected as having delirious states or other incapacities were excluded from the study. When patients asked for help regarding problems, for instance psychological problems, we provided professional help.

Phase 1: Qualitative approach

In the first part of the study we aimed to evaluate the perceptions of patients regarding nursing care in the ICU. Patients who had been ventilated for at least one day, and were admitted to the ICU for the first time were eligible for the study. Patients who were disoriented during mechanical ventilation; patients with cerebral neurological diseases; and patients who could not remember their stay in the ICU were excluded. We used the nursing tasks listed in the Dutch Nursing Profile as a theoretical framework, by using a topic-list, based on the tasks referred to in the profile. The National Council of Public Health published the Nursing Profile in 1988. This Nursing Profile sketches the profile of the professional practising nurse and is based on the definition of the American Nurses Association (1980). By using this profile, a clear description of the specific components of nursing care emerges. We chose to use a qualitative approach through interviews so that information regarding personal experience could be obtained. Initially, we considered a phenomenological approach because the purpose of phenomenology is to describe the perceptions of people, trying to understand the total subjective and objective perceptions as an individual. However, we wished like to know more about a number of aspects concerning the perception of nursing care. Since too much structure and redirecting was necessary to use the phenomenological approach, we decided to apply Maso's approach, in which data-collection, analysis and creating relations of possible theoretical insights exchanging among each other, seemed well suited (Maso, 1989). Finally, a qualitative approach was chosen using a semi-structured focused interview with a list of topics (Table 1). These interviews took place 6–14 days after transfer from the ICU to the ward.

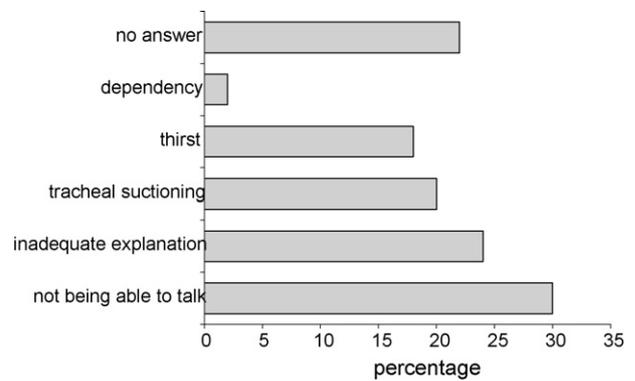


Figure 1 Annoying experiences in patients who were mechanically ventilated (%) (multiple answers possible).

This time window was deliberately chosen because earlier interviewing might have been influenced by critical residual illness. A purposive sampling technique was employed, and inclusion and exclusion criteria were identified (Morse, 1991). The interviews were recorded on tape and fully transcribed. Accordingly, the analysis (Maso, 1989) was conducted on two levels. Maso (1989) used the working methods of Becker and Geer (1960), and of Hyckner (1985) as sources of inspiration for the elaboration of an analytical procedure (Becker and Geer, 1960; Hyckner, 1985). The primary analysis consisted of six steps, and the secondary analysis takes place in four steps (Fig. 2). Accordingly, the collection of accumulating data with every subsequent patient was repeatedly analysed and related to possible theoretical insights (Maso, 1989) (Fig. 2). This procedure of analysis was used alternately after 3, 6, 9 and ultimately after 11 interviews. Since no more new findings emerged from the data and the saturation point was reached, further interviews would not yield additional information (Maso, 1989).

Table 1 Perception of nursing care: list of topics, used during the interview

- (1) What happened when tasks were undertaken concerning you? (Such as washing, making the bed). In what way was this done, and was there anything, that had a special significance to you? How did you experience the information given?
- (2) Did the nurses talk to you? If yes, what did they talk about?
- (3) Can you describe, what the nursing staff did for you, which gave you the feeling they cared for you?
- (4) What did the nursing staff do while performing technical duties, such as giving medicine, handling the mechanical ventilator or the ECG monitor?
- (5) What did you think of while being attached to all the machinery? What did you think about being dependent on this machinery?
- (6) What is your perception of the shift changeover of nursing staff (the handover and reporting) between nurses.
- (7) If there was a nurse at your bedside (like making the bed, and taking care of the feeding) what did you value about this?
- (8) What did you perceive as positive and what did you perceive as negative? (What was good and what was bad about this?)

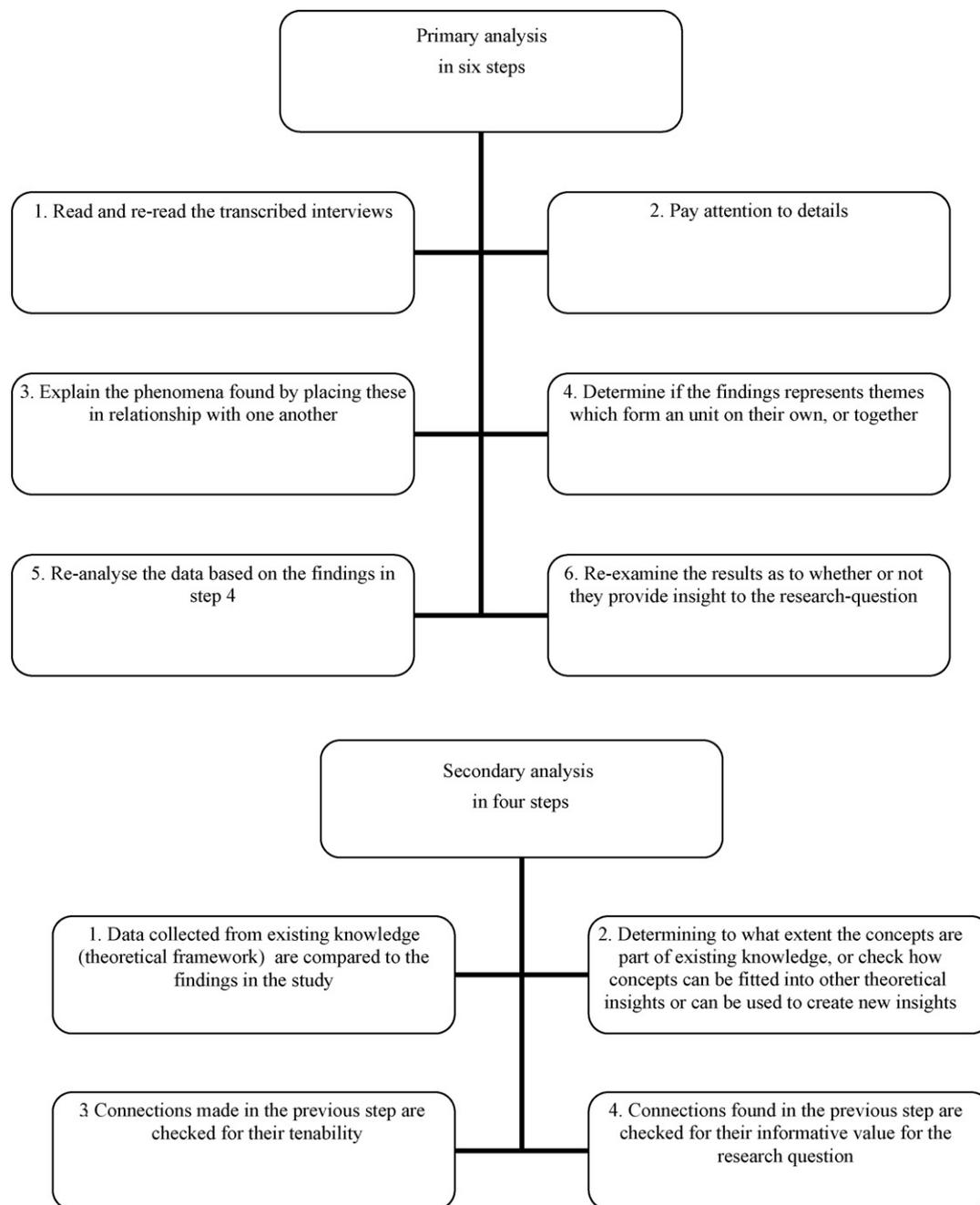


Figure 2 Schematic description of the analysis, following the principles of Maso (1989).

Reliability of the topics list was investigated by evaluating personal feelings or prejudices by other investigators in line with Maso (1989). Lincoln and Guba (1985) suggested that four factors can be used to assess the rigor of a qualitative study: creditability, transferability, dependability, and confirmability (Lincoln and Guba, 1985). The credibility of the data (validity) was studied by ‘peer debriefing’, which is the comparison of insights obtained by the investigator with the

insights of colleagues not involved in the study. Also by showing the transcribed interviews to four patients they indicated that the interpretation of the information they had provided was correct. Transferability of the data was studied by the use of thick descriptions relating to the context of the data collected. Dependability (reliability) and confirmability were studied through independent inquiry audits by external auditors.

Phase 2: Quantitative approach

In the second part of the study we aimed to explore patients' perceptions and experiences of their ICU stay and possible psychological problems related to this. Following a pilot study in 10 patients, subsequently, all patients in a 6-month period who stayed in the ICU >48 h and survived hospital stay were included in the study using a quantitative approach ($N=100$). Additionally, in this part of the study we were interested in the experiences of all patients admitted at our ICU and not only patients who were ventilated (phase 1). All patients received a questionnaire 3 months after hospital discharge for retrospective evaluation of their experiences that was returned anonymously. Validity of the items used in the questionnaire was sought by using the data collected in the interviews (phase 1), the literature and the results after consultation with the ICU nurses. After analysing the data, definite questions were formulated, which were understandable for the patients and mentioned by the patients as an important issue for them in the ICU. Cronbach's α coefficient was calculated for evaluating the internal reliability of the items of the questionnaire. The patients were asked about preparation for their ICU admission and support during their stay together with recollections of their stay and time on respiratory support. The questionnaire was divided in three domains i.e. preparation and support of the

patient by the ICU staff, recollection of their stay, recollections during mechanical ventilation in addition to an open-ended question (Table 3). Data were analysed using the SPSS version 11.0 programme. Categorical data were compared using chi-square test. SPSS was also used for the documentation of responses to the open-ended question by using frequency testing.

Findings

Phase 1: Qualitative approach

A total of 11 patients were interviewed: 8 surgical and 3 non-surgical patients. Characteristics of those patients are shown in Table 2, panel A. The primary analysis according to Maso (1989) was carried out first and yielded the following 10 categories: appreciation of the nurse; information and explanation given by the nurse; talking with the nurse; being attached to machines; technical performances of the nurse; basic care given by the nurse; transfer of shifts between the nurses; noise caused by the nurse and machinery; dreams and hallucinations; common organisational perceptions. A number of themes seemed to emerge from these categories, which narrowed down to one key theme. This key theme was support and was seen as a continuum from feeling supported by the nurse to not being

Table 2

Panel A: Perception of nursing care: characteristics of the patients ($N=11$)

Patient	Interview time after transfer ICU (days)	Diagnosis	Age (years)	Gender	ICU length of stay (days)	Ventilation (days)
1	7	Abdominal aortic aneurysm	67	Male	11	8
2	8	Exacerbation chronic demyelinating neuropathy	65	Male	8	4
3	7	Abdominal aortic aneurysm	67	Male	13	11
4	13	Pancreatitis	54	Male	21	14
5	11	Small bowel perforation	70	Female	6	4
6	8	ileus, renal dysfunctions	68	Female	6	4
7	6	Abdominal aortic aneurysm	60	Female	5	4
8	7	COPD	61	Female	20	20
9	6	Ruptured abdominal aortic aneurysm	73	Male	7	5
10	8	ileus, shock	68	Male	16	14
11	7	Pneumonia	66	Male	7	6

Panel B: Experiences of ICU stay: characteristics of the patients ($N=100$)

Mean \pm S.D.	$N=100$
Age	69.1 \pm 13.0
ICU length of stay	15.0 \pm 18.5
Apache II score	18.6 \pm 7.0

Table 3 Experiences of ICU stay: self-report questionnaire in three domains

Panel A: Preparation and support of the patient by the ICU staff

	<i>N</i>	%
Were you prepared for the admission at the ICU?		
Yes	20	40
No	30	60
Other	0	0
If yes, how did you perceive this?		
Excellent	10	50
Good	6	30
Poor	4	20
Bad	0	0
How did you perceive the first help at the ICU?		
Excellent	0	0
Good	28	56
Poor	6	12
Very poor	4	8
No answer	12	24
Did you get enough information about what you could expect in the ICU?		
Yes	20	40
No	15	30
Don't know	10	20
No answer	5	10
Did you understand the given information?		
Yes	25	50
No	11	22
Don't know	0	0
No answer	14	28
How did you perceive the support during your stay in the ICU?		
Excellent	18	36
Good	17	34
Poor	8	16
Bad	0	0
No answer	7	14
How did you perceive the attitude of the nurse? (Multiple answers possible - % total >100)		
Calmly	27	54
Hurried	4	8
Interested	28	56
Not interested	1	2
No answer	0	0
How did you perceive the attitude of the doctor? (multiple answers possible - % total >100)		
Calmly	33	66
Hurried	2	4
Interested	24	48
Not interested	1	2
No answer	0	0
Panel B: Recollection of their stay		
	<i>N</i>	%
Do you have memories of your stay in the ICU? If yes, describe these memories		
Yes	17	34
No	13	26
A little	19	38
No answer	1	2

Table 3 (Continued)

Panel B: Recollection of their stay

	N	%																
If yes, are these memories																		
Pleasant	19	53																
Unpleasant	10	28																
Very unpleasant	7	19																
Did you experience pain in the ICU? Did you get enough medication?																		
Yes	23	46																
No	17	34																
I don't know	10	20																
Did you get enough medication?																		
Yes	32	64																
No	11	22																
Other	7	14																
Did you experience noise in the ICU and if yes, how much did it disturb you?																		
Yes	20	40																
No	25	50																
Other	5	10																
If yes:																		
Much	13	65																
Little	3	15																
Very much	4	20																
Did you have sleeping problems while in the ICU? If yes, what was the most common cause of this?																		
Yes	24	48																
No	26	52																
If yes:																		
Noise	13	54																
Fear	6	5																
Pain	5	21																
Other	0	0																
			<table border="1"> <thead> <tr> <th colspan="2"></th> <th>Much of a burden</th> <th>Small burden</th> <th>No burden</th> <th>No answer</th> </tr> <tr> <th>N</th> <th>%</th> <th>N</th> <th>%</th> <th>N</th> <th>%</th> </tr> </thead> </table>						Much of a burden	Small burden	No burden	No answer	N	%	N	%	N	%
		Much of a burden	Small burden	No burden	No answer													
N	%	N	%	N	%													
What were annoying experiences for you when admitted in the ICU? (Multiple answers possible - % total >100)																		
Shortness of Sleep/rest	13	26	7	14	13	26	17	34										
Thirst	7	14	6	12	10	20	27	54										
Stomach tube	4	8	7	14	8	16	31	62										
Oxygen mask or tube	6	12	3	6	7	14	34	68										
Tracheal suctioning	6	12	5	10	8	16	31	62										
Noise of machines	5	10	6	12	10	20	29	58										
Being ventilated by a machine	6	12	4	8	10	20	30	60										
Conversations in the ICU	6	12	9	18	15	30	20	40										
Physical-therapy	0	0	4	8	14	28	32	64										

Panel C: Recollections during mechanical ventilation

	N	%
When you were mechanically ventilated were you prepared for this?		
No, not at all	16	32
Not possible due to time	10	20
Good	3	6
Fair	5	10
Poor	5	10
No answer	11	22

Table 3 (Continued)

Panel C: Recollections during mechanical ventilation		
	N	%
Did you have psychological problems after hospital discharge?		
If yes, was this? (Multiple answers possible - % total >100)		
If yes, would you appreciate professional help (family doctor or psychologist)?		
Yes	11	22
No	39	78
I don't know	0	0
If yes:		
Fear	8	50
Concentration disturbances	2	12.5
Hallucinations	2	12.5
Depressions	2	12.5
Forgetful	2	12.5
If yes: would you appreciate professional help (family doctor or psychologist)?		
Yes	7	64
No	1	9
I don't know	3	27
Panel D: Open-ended question (Multiple answers possible)		
	N	
Did you have other experiences in the ICU who were important to you?		
If yes, would you describe this experiences?		
Relatives need more information and preparation	3	
Nurses and doctors have to realise that some patients are conscious (anxiety, disturbing)	2	
Too short of rest/sleep	6	
Hallucinations and dreams were not taken seriously by nurses and doctors	5	
Communication with the nurse was very difficult when on the ventilator	8	
Hurrying while busy with washing	3	
Complete and honest information concerning illness	4	
Compassion, sympathy, perceived as very important	4	

supported with movement back and forth along the continuum. This key theme was central to each of the three categories emerging from this data. In the secondary analysis, 3 of the 10 categories were related to existing theoretical insights, i.e. (1) providing the seriously ill patient with information and explanation (Grypdonck, 1996), (2) placing the patient in a central position (Morse, 1996) and (3) personal approach by the nurse (King, 1981).

Providing the seriously ill patient with information and explanation

When providing patients with information and an explanation, patients were more aware of what was going to happen so that they could focus on feeling more relaxed and better able to handle the stress:

... 'Certainly, then when you know what you're dealing with. Yes, and I find that one can prepare

oneself. Yes, I do feel more relaxed because of that, and I am able to handle stress much better' (patient 1).

The explanations and the instructions during ventilation were perceived as being reassuring, resulting in less fear and insecurity:

... 'Yes, they explained everything well. And if the ventilation machine next to me stopped for a moment they told me about it. Or when they were trying out something else. You knew that they would explain what they were doing first. Yes, in my opinion you'd worry less about things' (patient 6).

Information concerning their illness and the course of the illness should be complete and honesty was perceived as important. Knowing 'why' was supportive and reduced fears:

... 'I did say that I wanted honest information. And even they couldn't know everything that was

going to happen, naturally, but that the way things were at that time looked very promising. They told me that it was no use to think about things that "could" happen. Yes and then I thought: well, they are right. Yes and then it felt like a weight dropping off my shoulders. Yes, I appreciated that very much' (patient 5).

Placing the patient in a central position

Important to patients is the fact that nurses try to keep seeing them as a human being and as the centre of their attention in the ICU. Especially putting them central, meaning that humane care is crucial:

... 'Yes, there was a nurse who held my hand, came to sit with me on my bed and she stayed until I felt more relaxed again. Now, I feel that it helped me very much. I told my wife about that later on, and even now I still know who the nurse was. I was thinking then, gosh I wish the nurse who was there the other night did the same. I think I would have had a far better night' (patient 2).

Not only the amount of technical equipment, but also encouragement providing care and 'cheering them up' was perceived by patients as being life-saving factors. When talking was not possible, the aid of nurses in pointing out letters and writing was perceived as stress relieving:

... 'Yes, and what was very annoying of course was that you couldn't talk. You just let things wash over you sort of. But I have to say that it makes you feel kind of scared, I mean, trying to talk and not being able to... You can't say what's bothering you or anything, and you can't ask for anything. Anyway, then the nurse said: I'll get a paper and then you write it down. But I don't write much even at home, so I just hoped it would work... Well, it was really difficult, it seemed as though my hand was too weak or something... Then they tried by pointing out letters, which was quite hard at first, but that worked eventually. Yes, the nurses try their best to help you out... You truly appreciate it then, I think it reduces the stress' (patient 9).

From these interviews, it was clear that not only technology and the expertise of nurses were important to patients, but that human aspects including compassion, encouragement, attention, giving comfort, relieving fear and creating security were also important. The most vital aspect of nursing care as experienced by patients was support. Patients viewed their ICU stay as a situation that they had to get through and

non-supportive care was found to hinder their recovery. If the nurses responded very slowly when patients rang the bell, this caused feelings of helplessness, hurt, powerlessness and dependency:

... 'Yes and then you have rung the bell and no one shows up. And sure, there are emergencies, and I understand that completely, but waiting on the bedpan for half an hour isn't exactly fun either. But it could have been that they thought: just wait for a while. Yes, I had that feeling. I mean, you could see them having coffee together and no one came. You know, it made me feel helpless, and powerless. It's hard to describe. You feel, what can I say, you feel hurt and you could easily start to cry. Yes and then I thought oh please let someone come, don't let a person who is so dependant wait so long. That is important, right? I mean, I know that on such a ward they also look after the other things such as the equipment and so on. And there are very ill people there too, but surely they should pay some attention to what's going on? For a patient it's very important I can tell you... ' (patient 8).

When nurses did not take a patient seriously or even reacted aggressively to hallucinations or dreams this caused feelings of not being understood, anger, fear, feeling ill at ease, not understanding what was going on and also the feeling of not being treated as a human being:

... 'Well, that he didn't take me seriously I mean, and they didn't tell me what was going on. They didn't have much experience with it I guess. I um... I mean, they could have coped with it better than that... Yes I mean they just reacted aggressively when I told them I was seeing things. They said: "Well, sir... listen up" and in such a tone of voice... I mean, it's just no attitude. I know I saw things that weren't there, but that's no reason to react that way. No, I want to share that. I can't keep that to myself. I was angry because of that, and not just angry but sad too. Yes, I mean you want to be treated as an adult instead of a child, right? Yes, I mean I'm not an engine that needs to be fixed, I mean, I'm a human being... And well, I just don't think that's the right way to deal with people' (patient 10).

Most patients also reported discomfort due to the noise of loud voices and conversations between nurses. When the personnel made a lot of noise during conversations by talking too loudly and wearing clogs, the participants often got the feeling that they were not improving. The fear of not clinically improving combined with the noise caused the par-

ticipants to feel tired and unable to handle the situation adequately:

... 'Yes then I thought, please be a bit quieter. I can hear all of it. Yes it's hard to explain but if you can't sleep, can't shut yourself down so to speak, and being afraid of all that may happen makes you scared. Yes all that makes you feel that you can't handle things anymore, you think: I can't hang on anymore' (patient 11).

Personal approach by the nurse

Treatment was perceived as comforting, giving a safe feeling. It was judged important how the nurse dealt with them as a person; this was often not described directly as 'behaviour':

... 'I was very scared and insecure in the beginning. However when the nurse is kind to you and gives you the feeling they sympathise, it is a very comforting feeling' (patient 4).

Certain types of approach resulted in patients being reluctant to ask the nurse questions:

... 'I remember nurses who always looked angry. I did not dare to tell them while they were at work checking on the pumps and everything that I was so thirsty. I would rather have had someone who looked nice and who did not run off immediately but asked me if I needed anything instead' (patient 7).

Results

Phase 2: Quantitative approach

During the study period (6 months) 308 patients were admitted. One hundred patients stayed in the ICU for more than 48 h. Following the interviews, we sent questionnaires to all of those patients. Characteristics of those patients are shown in Table 2, panel B ($N=100$). Categorical data were compared on differences using the chi-square test. However, the differences were not significant. Internal reliability was measured computing Cronbach's α which was reasonable and varied between 0.73 and 0.78. Sixty-two questionnaires were returned anonymously. Twelve patients had no recollection of their stay in the ICU, or had already died at home, leaving 50 questionnaires for evaluation. Most of the patients were acute admissions to the ICU (60%). Sixty percent of all patients and 52% of the patients who were venti-

lated were not prepared for their admission to the ICU. Half of the patients had only fragmentary recollections of their stay. Pain (46%) and noise (40%) (Table 3) were the most frequent complaints. Of the patients experiencing sleeping disorders (48%), 54% of them associated this with the presence of noise (Table 3). Most annoying procedures and events during admission were not being able to talk, tracheal suctioning, thirst, and inadequate explanation of actions taken by the ICU staff (Fig. 1). Eleven patients (22%) had psychological problems after hospital discharge, which were related to fear, the inability to concentrate, depression, hallucinations and a bad memory (Table 3). Seven patients would have appreciated professional help (family doctor or psychologist) (Table 3).

Discussion

A number of themes emerged from the interviews with patients pertaining to their experiences although one key theme, support, dominated. This was seen as a continuum from the feeling of being supported by the nurse to not being supportive. This key theme was central to each of the three categories emerging from this data: (1) providing the seriously ill patient with information and explanation, (2) placing the patient in a central position and (3) personal approach by the nurse (phase 1). The responders to the questionnaire experienced sleeping disorders (48%), mostly related to the presence of noise (54%). Psychological problems after ICU stay were reported by 11% of the patients, i.e. fear, inability to concentrate, depression and hallucinations (phase 2). Furthermore, results of both studies demonstrated the attitude of the staff (nursing and doctors) was significant. This included the importance of explanation when mechanically ventilated and taking psychological problems seriously. Patients experienced these perceptions in both studies as supportive or non-supportive.

Providing the seriously ill patient with information and explanation

Patients especially perceived that complete information and clear explanation was an important concept in the interviews as well as in the questionnaires. In addition, patients perceived clear explanations that were given to the family as being supportive and gave the feeling of being cared for, thus enhancing feelings of confidentiality and security, which confirms previous data (Asbury, 1985;

Burfitt et al., 1993; Russell, 1999). In contrast, patients may state that personal needs should be considered and that they should be asked whether or not they wish to receive detailed information (Grypdonck, 1996). This is in accordance with our data, since some patients indicated that the process of being shown the ICU beforehand had been helpful in being able to prepare better or to reduce fear and nervousness. Previous studies concur with this finding, i.e. giving careful information and explanation of procedures beforehand relieved discomfort and distress, disappointment and insecurity for the patient (Johnson, 1972; Bergbom-Engberg and Haljamae, 1988b; Turner et al., 1990; Jablonski, 1994; Hafsteindottir, 1996). Moreover, talking, giving instructions, explanations and encouragement prepared the patient for a specific procedure thus potentially reducing complications (Morse and O'Brien, 1995). Finally, ICU patients frequently wish to talk about their experiences. This emphasises the necessity of some form of follow up (Lof et al., 2006).

Placing the patient in a central position

Communication is important to critically ill patients (Maddox et al., 2001; Alasad and Ahmad, 2005). Our findings showed that feelings of fear were reduced during the weaning period of mechanical ventilation if nurses took time to communicate with the patient, thus enhancing the weaning process. Help with writing and pointing out letters during the ventilation period was perceived as safe and supportive. However, when the nurses did not adequately attempt to understand example the patient may feel that nurses do not care enough. This makes patients angry and sad, which confirms previous data (Ashworth, 1980; Bergbom-Engberg and Haljamae, 1988b; Green, 1996; Hall, 1996; Happ, 2000; Magnus and Turkington, 2006).

In our study, patients reported that the fact they were being taken seriously when having hallucinations or disturbing dreams gave feelings of security and comfort. In contrast, when patients had the feeling not being taken seriously or were approached with aggressive behaviour by the attending nurse, they reported feelings of fear, not being understood, not knowing what was happening, or inhumanely treated. Also a feeling of embarrassment due to loss of self-control was described. This confirms previous data reporting the importance of communication in relation to psychological function (Ballard, 1981; Glen, 1991; Morse and O'Brien, 1995; Roberts et al., 2006). In situations where nurses asked colleagues to look at the patient they were attending without inform-

ing the patient, or when other personnel often came in during washing, this induced the feeling of being "just a case" with a lack of personal interest and a feeling of lack of control. This feeling of powerlessness was also reported in other studies (Stanton, 1991; Maddox et al., 2001). Investigating patient empowerment in an ICU situation using open-ended interviews in 11 ICU patients, showed that a positive environment that encouraged feelings of value and motivation and in which the patient felt safe, received additional care and participated as the patient wished had a positive influence and reduced feelings of powerlessness (Wahlin et al., 2006).

Personal approach by the nurse

The personal approach and the actions of the nurse in this study was perceived as being comforting, relaxing with feelings of compassion. When the personal approach by the nurse was positive, this was considered a first step in recovery. Sometimes patients described the personal approach as negative: "she looked mad", "she looked angry". That caused patients to be reluctant to ask questions of the nurse and reduced confidence. ICU patients are very sensitive to the attitudes and behaviour of staff, who may either increase patient's anxiety and vulnerability or make them feel more safe and confident (Bergbom-Engberg and Haljamae, 1988b; Burfitt et al., 1993; Jablonski, 1994; Laitinen, 1996; Holland et al., 1997; McKinley et al., 2002; McCabe, 2004). Some patients in our study indicated that the caring behaviour of the nurse and their continuous support relieved their fears and worries in a way that they could concentrate on their recovery and rehabilitation. Caring behaviour was also described as sweet, nice, compassionate, showing personal interest in the patient as well as the family as confirmed in other studies (Swanson, 1990; Burfitt et al., 1993; Adamson et al., 2004).

Hallucinations, noise, sleeping problem, psychological problems

Patients had only fragmentary memories after ventilator treatment and discharge, confirming previous data (Turner et al., 1990; Lof et al., 2006). In our study, patients experienced sleeping disorders related to the presence of noise and complained of psychological problems after ICU stay. Most of these patients complained of fear, other problems were related to the ability to concentrate, depression and hallucinations. Turner et al. (1990) interviewed

100 patients within 48 h following ICU discharge. In accordance with our data, when asked about recollections regarding procedures and events only 50% of the patients had memories of their stay in the ICU. Although tracheal suctioning was generally considered unpleasant, careful explanations of procedures were considered important to relieve discomfort. Sensory overload, anxiety, and pain were also reported in other studies (Bergbom-Engberg et al., 1988a; Stanton, 1991; Barnard and Sandelowski, 2001).

Previous studies demonstrate both differences and comparable findings. Adamson et al. (2004) reported three themes that differ from our findings: recollection, responses and comfort/discomfort. However, in contrast with our study (performed 6–14 days after ICU transfer) the interviews were undertaken 6 months after hospital discharge. It is possible that the difference in time influenced the memories of the patients (Adamson et al., 2004). In contrast, Russell found similar findings to our study, interviewing 86 patients 6 months after discharge (Russell, 1999).

Differences between study findings may be related to differences in ethnic, socio-economical and theological background. However, all in all, our findings do not suggest that things have changed much during the past two decades concerning patient experiences of nursing care, as our findings were consistent with those of studies performed from 1970 to 2007 (Johnson, 1972; Magnus and Turkington, 2006). Therefore, our findings may reflect a universal nursing phenomenon in relation of the nursing care provided in the ICU.

Limitations

This is a single centre study in the Netherlands, which implies that the perceived experiences of patients elsewhere may be different due to differences in case mix, staffing, but also ethnic, socio-economical and theological background. Previous data showed both parallel findings and differences (Russell, 1999; Adamson et al., 2004). Also, the mean age of patients was 69, reflecting the average ICU population in our setting. It is possible, that perceptions of younger patients are somewhat different. Moreover, the interviews were taken while the patients were still in the hospital. Their perceptions may have been influenced by the fact that they had not physically recovered completely. In addition, the interview was taken retrospectively and not at the time the patient received nursing care in the ICU. A further limitation is the lack of assessment of delirium by

specific scores, however we checked the presence or absence of delirium in the participants, by asking the opinions of the nurses and doctors involved in the daily care of the patients, and included information from close relatives. Another potential drawback is that only 50 of the 100 questionnaires could be evaluated. Finally, half of the patients had only fragmentary recollections of their stay.

Conclusions

Taking care of the patient is an important part of the treatment of critically ill patients. Although the nurses' expertise, technical skills and medical equipment are perceived as important by patients, as they are part of necessary life saving interventions, caring behaviour, relieving the patient of fear and worries, may help them to concentrate on their recovery, and is regarded as most valuable. Nurses should be aware that patients sometimes perceive that increased attention to technical equipment decreases the patients' trust. Careful and adequate information to patients is an important factor to improve the patient–nurse relationship. The importance of these findings for clinical practice may be, that being aware of this, we can improve the quality of care in the ICU.

Competing interest

The author(s) declare that they have no competing interests.

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José G.M. Hofhuis performed the interviews, analysed and interpreted the data and drafted the article.

Peter E. Spronk conceived of the study, contributed to the interpretation and analysis of the data, and revised the manuscript for important intellectual content.

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