

**A wish to be near: Experiences of close relatives within intensive care, from the
perspective of close relatives, formerly critically ill people
and critical care nurses**

Åsa Engström

Division of Nursing

Department of Health Science

Luleå University of Technology

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*Thoughts of my family made me struggle on.
I don't know, but my children were the ones
who drove me on. I had to fight on. I saw
how they and my husband cared for me and
had to manage everything. Then I felt I can't
fail them; I have to continue to struggle*

(Engström & Söderberg, 2007, p. 573)

CONTENTS

| | |
|--|----|
| ABSTRACT | 7 |
| ORIGINAL PAPERS | 8 |
| INTRODUCTION | 9 |
| Close relatives of critically people in intensive care | 9 |
| Close relatives from the perspective of critically ill people | 11 |
| Close relatives of critically ill people from critical care nurses' perspective | 13 |
| Follow-up visits after discharge from the ICU | 15 |
| Critical reflection on the literature review and rationale for the thesis | 17 |
| THE AIM OF THE DOCTORAL THESIS | 19 |
| METHODOLOGICAL APPROACH | 20 |
| The naturalistic paradigm | 20 |
| Context | 20 |
| Participants and procedure | 21 |
| <i>Paper I</i> | 22 |
| <i>Paper II</i> | 23 |
| <i>Paper III</i> | 24 |
| <i>Paper IV</i> | 24 |
| Data collection | 26 |
| <i>Qualitative research interviews</i> | 26 |
| <i>Focus-group discussions</i> | 27 |
| Data analysis methods | 29 |
| <i>Qualitative thematic content analysis</i> | 29 |
| <i>Phenomenological hermeneutic interpretation</i> | 30 |
| Ethical consideration | 32 |

| | |
|--|----|
| FINDINGS | 34 |
| Paper I The experiences of partners of critically ill persons in an ICU | 36 |
| Paper II Receiving power through confirmation: the meaning of close relatives for people who have been critically ill | 38 |
| Paper III Close relatives in intensive care from the perspective of critical care nurses | 40 |
| Paper IV Re-visiting the ICU. Experiences of follow-up visits to an ICU after discharge: a qualitative study | 43 |
| DISCUSSION | 46 |
| METHODOLOGICAL CONSIDERATIONS | 53 |
| CONCLUDING REMARKS | 57 |
| CLINICAL IMPLICATIONS | 57 |
| SUMMARY IN SWEDISH - SVENSK SAMMANFATTNING | 60 |
| ACKNOWLEDGEMENTS | 70 |
| REFERENCES | 73 |
| Paper I | |
| Paper II | |
| Paper III | |
| Paper IV | |

A wish to be near: Experiences of close relatives within intensive care from the perspective of close relatives, formerly critically ill people and critical care nurses

Åsa Engström, Division of Nursing, Department of Health Science, Luleå University of Technology, Luleå, Sweden.

ABSTRACT

The overall aim of this doctoral thesis was to describe the experiences of close relatives within intensive care, from the perspective of close relatives, formerly critically ill people and critical care nurses. Data were collected by means of qualitative research interviews with close relatives of people who had been critically ill and cared for in an intensive care unit (ICU) and with the people themselves. Data were also collected by means of focus-group discussions with critical care nurses. Collected data were analysed using qualitative thematic content analysis and phenomenological hermeneutic interpretation. This thesis reveals that it was a frightening experience for close relatives to see the person critically ill in an unknown environment. It was important to be able to be near the ill person. Showing respect for and confirming the dignity of the ill person were essential. The uncertainty concerning the outcome for the ill person was hard to manage. Close relatives wanted to feel hope, even though the prognosis was poor.

People who had been critically ill had felt their close relatives' presence. Through the help of close relatives they felt they were understood and safe. Close relatives made it possible for them to do various things, which were appreciated, but they also engendered feelings of guilt. They realized their own, and the close relatives' significance, which gave them the power to continue the struggle. The presence of close relatives was taken for granted by critical care nurses. Information from close relatives made it possible for critical care nurses to provide personal care for the critically ill person. Critical care nurses supported close relatives by giving them information and being near. Close relatives were described as an important but demanding part of the critical care nurses' work.

The possibility for people who had been critically ill, and their close relatives, to return together to the ICU for a follow-up visit after discharge and talk about what happened during and after their stay in the ICU was appreciated. Receiving explanations and being able to discuss one's experience were valuable. Meeting the ICU staff again enabled them to express their gratitude for their work, to give opinions about the care and to suggest improvements.

This thesis shows that the critically ill person is the focus of close relatives' existence. The uncertainty of the time causes close relatives' suffering and they felt vulnerable. To be able to be close to the critically ill person, to be allowed to participate in and receive explanations about what was happening and why, to be met by dignity and to be able to keep hope alive are all prerequisites for enduring a radically changed everyday life which close relatives experience when someone they love is, or has been, critically ill. The crucial challenge is how these needs can be met by the staff of the ICU.

Keywords: close relatives, critical care nurse, critically ill, interview, phenomenological hermeneutic interpretation, qualitative thematic content analysis, dignity, hope, shared understanding uncertainty, vulnerability

ORIGINAL PAPERS

This doctoral thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I. Engström, Å., & Söderberg, S. (2004). The experiences of partners of critically ill persons in an intensive care unit. *Intensive and Critical Care Nursing*, 20, 299-308.
- II. Engström, Å., & Söderberg, S. (2007). Receiving power through confirmation: the meaning of close relatives for people who have been critically ill. *Journal of Advanced Nursing*, 59, 569-576.
- III. Engström, Å., & Söderberg, S. (2007). Close relatives in intensive care from the perspective of critical care nurses. *Journal of Clinical Nursing*, 16, 1651-1659.
- IV. Engström, Å., Andersson, S., & Söderberg, S. (submitted). Re-visiting the ICU. Experiences of follow-up visits to an ICU after discharge: a qualitative study. *Intensive and Critical Care Nursing*.

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INTRODUCTION

This doctoral thesis focuses on close relatives within intensive care. When a person becomes acutely, critically ill it also impacts on their close relatives. The admission of an ill person to an intensive care unit (ICU) changes close relatives' everyday life radically and allows little time for them to adjust. In this thesis I will describe experiences of close relatives of critically ill persons during and after their stay in ICUs, and how close relatives' needs might be met. The thesis has a qualitative design and is anchored in the naturalistic paradigm.

Close relatives of critically ill people in intensive care

A close relative of a critically ill person is someone the ill person trusts and relies on, someone who cares about the ill person. A close relationship is a relationship that has extended over a period of time and involves a shared understanding of closeness (Harvey & Omarzu, 1999). The close relative can be a family member, a spouse, a partner or a friend; a loved one who is crucial and significant for the ill person and with whom they have a positive emotional relationship (cf. Eriksson & Bergbom, 2007). A close relationship might not include or be restricted to a biological or civil relationship (Bergbom-Askwall, 2000; Burr, 2001). A close relative of a critically ill person in an ICU can bring with them a life history of experiences and feelings shared by the ill person and the close relative (Walters, 1995).

Without forewarning close relatives' lives can be brought to halt when a person becomes acutely, critically ill (Jumisko, Lexell & Söderberg, 2007). The worst situation for close relatives in an ICU is when they do not receive sufficient information about the critically ill person's situation and prognosis (Bond, 2003; Hughes, Bryan & Robbins, 2005; Kosco & Warren, 2000). Close relatives of critically ill people have described how they felt vulnerable and resourceful at the same time, and they experienced uncertainty regarding what to expect and how to act in the ICU (Ågård & Harder, 2007). Those close relatives who had difficulties understanding information withdrew from communication with the staff, did not adjust to the system and could feel insulted by the staff, while those close relatives who understood information and messages, adjusted well to the system, and were acknowledged by the staff (Söderström, Saveman & Benzein, 2006). While close relatives recognize that the ill person is the critical care nurse's priority they also experience a profound difference between critical care nurses who make efforts to be there with and for, the close relatives as well as the ill person, and critical care nurses who do not (Eggenberger & Nelms, 2007).

Research into the needs of close relatives within intensive care, is principally carried out by means of an assessment tool developed by Molter (1979). This consists of a list of 45 needs that relatives can rate on a four-point Likert scale. Leske (1986) modified this tool by adding an open-ended item and calling it the critical care family needs inventory (CCFNI). This has subsequently been used in numerous studies (e.g. Azoulay et al., 2001, Davis-Martin, 1994, Leske, 1986, McIvor & Thompson, 1988, Mendonca & Warren,

1998, Miracle & Hovecamp, 1994). There is some agreement in studies using CCFNI concerning the most important needs of close relatives of critically ill people in ICUs. These are the need for information and hope (Holden, Harrison & Johnson, 2002; Verhaeghe, Defloor, van Zuuren, Duijnste & Grypdonck, 2005).

Close relatives' responses to the CCFNI have been compared to those who participated in an interview. There was agreement on the priority needs for information about, and access to, the critically ill person, but their own personal needs were accorded low priority. Two major needs emerged from the interviews that are not represented on the CCFNI: the need of close relatives to provide support and the need for them to protect the ill person (Burr, 1998), as close relatives have described themselves as the critically ill person's protector (Chambers-Evans, 2002; Hupcey, 1999). Close relatives have described a need to feel hope that the critically ill person will remain alive, and if that is no longer possible, they hope the critically ill person will die peacefully and with dignity (Burr, 1998).

Close relatives from the perspective of critically ill people

To be critically ill in an ICU means to be stricken by a sudden, unexpected, and often life-threatening illness. This can be acute illness or trauma; exacerbation of a chronic illness, or an episode of a previously unknown illness (Norton, 2005). The critical ill person loses freedoms ordinarily associated with being able to act as a fully independent human being (Pellegrino, 1982). Being critically ill in an ICU often means being confined to bed,

intubated or having a tracheostomy, being artificially ventilated and also having arterial lines, central venous lines, drains and a urinary catheter inserted. Circulation and respiration are monitored via electrodes, and the critically ill person might undergoes unpleasant nursing-care activities such as the suction of secretion from the air passage (Granberg, Bergbom-Enberg & Lundberg, 1996; Wikström & Sätterlund Larsson, 2003). The need for ventilatory support is described as frightening because of not being able to breathe on your own or to talk to close relatives or staff (Arslanian-Engoren & Scott, 2003; Gjengedal, 1994; Magarey & McCutcheon, 2005).

Critically ill people upon waking up after sedation has worn off have described feelings of emptiness and disorientation. The first real memories are often described as being the presence of close relatives because it meant they were in contact with something real to them (Granberg, Bergbom-Enberg & Lundberg, 1998; Hupcey, 2000). People who have been critically ill have described their close relatives as an important support during their stay in an ICU and that their presence gave them a feeling of protection (Arslanian-Engoren & Scott, 2003; McKinley, Nagy, Stein-Parbury, Bramwell & Hudson, 2002). Critically ill people have experienced feelings of causing suffering among their close relatives because of their critical condition and situation (Bergbom & Askwall, 2000). This evoked feelings of guilt, which increased and extended their own levels of suffering.

Critically ill people received the greatest help from visitor with whom they had a good relationship, on people whom they could rely and who cared for them. They said that

they did not want visits from those who did not really like them, who were critical, or judgmental (Bergbom & Askwall, 2000). In an ICU in Sweden it has been described that 75 percent of the critically ill persons had visitors; the most frequent visitors were spouses and children (Eriksson & Bergbom, 2007). The quality of the support gained from close relatives when critically ill is described as being more important than the actual number of visitors (Hupcey, 2001).

Close relatives of critically ill people from critical care nurses' perspective

Critical care nursing includes caring for the relatives of critically ill people and one important part of nursing care is giving support. Support means caring for ill people and their close relatives and that includes giving hope, involving close relatives in the care, providing support services and spiritual care (Wilkin & Slevin, 2004). According to Ciccarello (2003), critical care nurses who have been able to discuss the situation with the ill person and their close relatives feel they are better able to understand their needs. In meeting the needs of close relatives, critical care nurses said they were helping to improve the outcomes for ill people in the ICU (Gavaghan & Carroll, 2002). Close relatives are seen as a resource for critical care nurses if they can contribute personal information about the critically ill person (Söderström, Benzein & Saveman, 2003; Williams, 2005).

Critical care nurses have perceived the effects of close relatives visiting in ICUs to be, in order, most positive on effects on the critically ill person, followed by effects on the nurses, and finally as being least positive the effects on the close relatives themselves (Plowright,

1998). Open visiting for close relatives is described as implying a greater burden for critical care nurses, but it is experienced as worthwhile because it creates an atmosphere which is beneficial to the convalescence of the ill person (Marco et al., 2006).

There are examples of inhibiting and non-inviting interactions with close relatives by critical care nurses in ICUs (Eggenberger & Nelms, 2007; Hupcey, 1998; Söderström et al., 2003), e.g. critical care nurses used different strategies for developing relationships with close relatives, but they also used strategies that inhibited relationships (Hupcey, 1998). Caring for the critically ill person is what critical care nurses describe as their priority, and consequently they feel torn between caring for the critically ill person, and recognizing their responsibility towards close relatives (Cronqvist, Thoerell, Burns & Lützén, 2001; Farrell, Joseph & Schwartz-Barcott, 2005; Stayt, 2007). Critical care nurses find it demanding to communicate with close relatives about the impending death of a critically ill person (Ciccarello, 2003; Peel, 2003; Scullion, 1994). In addition to caring for the ill person, the critical care nurse must also attend to the close relatives' anxiety (Kendrick & Cubbin, 1996).

Takman and Severinsson (2004, 2005, 2006) has used the CCFNI scale concerning perception of the needs of close relatives among critical care nurses and other staff. Those critical care nurses, who had themselves experiences of being ill or being a close relative in an ICU, placed a higher value on involvement than those without such experiences, while physicians with such experience scored higher on information and predictability than those

without. Age, professional experience and sex also seemed to affect the ICU professionals' perceptions of the needs of close relatives (Takman & Severinsson, 2005).

Follow-up visits after discharge from the ICU

After discharge from the ICU people who have been critically ill have described that they felt more sensitive and experienced fatigue as well as difficulty relaxing, concentrating and separating dreams from reality (Karlsson & Forsberg, 2008). People who have been cared for in ICUs have described an overall impression of the ICU as one of themselves being very sick and unable to relate events that occurred other than as a series of spasmodic interruptions. Common complaints after discharge from intensive care include: amnesia, not remembering one's stay in the ICU; or having patchy or delusional memories.

Nightmares, hallucinations and confusion are commonly described and reported to be very distressing (Hafsteindóttir, 1996; Löf, Berggren & Ahlström, 2006; Ringdal, Johansson, Lundberg & Bergbom, 2006; Roberts & Chaboyer, 2004).

There are various reasons why people who have been critically ill and cared for in an ICU should experience memory loss and hallucinations: the illness and its treatment; metabolic disturbances; delirium; alcoholic or drug withdrawal; sleep deprivation and ingestion of multiple drugs (Jones, Griffiths & Humphris, 2000). The depth of sedation has an impact on critically ill peoples' perception of stressful experiences; light sedation compared with heavy seems to increase the risk of perceiving experiences in the ICU as stressful and bothersome. This is also true of a longer ICU stay and being admitted as an emergency

(Samuelson, Lundberg & Fridlund, 2007). After being critically ill, people have often said that they commonly tried to rationalise their unreality and had memories of struggling to hang on to reality. The return to reality was clearly described and was associated with the beginning of recovery; this transition was helped by the presence of close relatives (Magarey & McCutcheon, 2005).

Mood changes, inability to cope, the need to talk about one's ICU experience and indistinct memories of the ICU have made recovery at home difficult for the people who had been critically ill, and also for their close relatives (Hall-Smith, Ball & Coakley, 1997). Being dependent on one's close relatives to manage everyday life after being critically ill is described as demanding (Maddox, Dunn & Pretty, 2001; Parker, 1999), and close relatives often provide informal care giving after that the ill person has been discharged and returned home (Foster & Chaboyer, 2003; Johnson, Chaboyer, Foster & van der Vooren, 2001).

There is need for explanations and visits to the ICU to put formerly critically ill people's experiences into context (Crocker, 2003), and follow-up visits after discharge from the ICUs have been suggested as a valuable way to meet this need in many studies (e.g. Cutler, Brightmore, Colqhoun, Dunstan & Gay, 2003; Griffiths & Jones, 2002; Hall-Smith, Ball & Coakley, 1997; Pattison, Dolan, Townsend & Townsend, 2007). One of the main clinical activities in connection with the follow-up visit can be to measure the quality of life after intensive care, using various quality-of-life scores (Glendinning, 2001). Others (Jones,

Humphris & Griffiths, 1998) believe that both people who have been critically ill and their close relatives need the opportunity to be debriefed about the illness experience and the time spent in the ICU by staff who were involved in their care, again this can be achieved by follow-up visits. Diaries written for people during their critical illness can also make it easier for them and their close relatives to understand what happened and to fill in memory gaps, which reduce the agony and the terrifying memories (Bergbom, Svensson, Berggren & Kamsula, 1999; Bäckman & Walter, 2000; Combe, 2005; Roulin, Hurst & Spirig, 2007).

Critical reflection on the literature review and rationale for the thesis

The literature review shows that when a person becomes acutely, critically ill it affects their close relatives. Research is principally aimed at ranking the needs of close relatives. Information about the critically ill person and the ability to feel hope are needs that are ranked high, and described as important by close relatives within studies with a qualitative design. Research describing the subjective experience of critical illness from the perspective of close relatives of critically ill people within the context of everyday life is scarce. The literature review further shows that becoming critically ill and cared for in an ICU is a difficult experience. The experience of disorientation and being unable to breathe or speak by oneself is especially trying. In this situation, close relatives are appreciated sources of making the ill person feel protected. The studies within this area are mostly qualitative and state that close relatives are important to the ill person, but studies describing the meaning of close relatives for people who have been critically ill are rare.

Furthermore, the literature review shows that critical care nurses express difficulties when they have to prioritize taking care of the critically ill person over their close relatives. The close relatives are seen as a possible source of more information about the critically ill person and a support for them. The experiences of close relatives within intensive care from the critical care nurses' point of view need further research. The literature review also shows that critical illness affects not only the ill person and their close relatives during the stay in the ICU and the hospital, but also in their everyday life afterwards. Not remembering it or having delusional memories about one's stay in the ICU is frustrating. Close relatives might be able to fill in some of these memory gaps, but can have unanswered questions themselves and follow-up visits in the ICU, together with a personal written diary, are suggested as an intervention.

To summarize; further research is needed to enhance our understanding of close relatives' experience and how their everyday life is affected in order to be able to understand their needs within intensive care. Knowledge about what close relatives of critically ill people are forced to face is the foundation for being able to support them. To gain this knowledge the experiences of close relatives of people who are or have been critically ill will be described from three perspectives; from that of close relatives (I, IV), from that of people who have been critically ill (II, IV) and from that of critical care nurses (III). Increased knowledge about close relatives and their experiences from these perspectives provides us with an opportunity to improve and change nursing care within intensive care so that it answers the needs of close relatives.

THE AIM OF THE DOCTORAL THESIS

The overall aim of this doctoral thesis was to describe the experiences of close relatives within intensive care from the perspective of close relatives, formerly critically ill people and critical care nurses. From the overall aim specific aims were formulated as follows:

Paper I The aim was to describe partners' experiences when their critically ill spouse was receiving care in an intensive care unit.

Paper II The aim was to elucidate the meaning of close relatives for people who have been critically ill and received care in an intensive care unit.

Paper III The aim was to describe critical care nurses' experiences of close relatives within intensive care.

Paper IV The aim was to describe post-discharge follow-up visit to an ICU as experienced by both people who had been critically ill and cared for in an ICU and their close relatives.

METHODOLOGICAL APPROACH

The naturalistic paradigm

This doctoral thesis is anchored within the naturalistic paradigm and has a qualitative approach. A paradigm, according to Kuhn (1996), is a way of looking at the world and science. Denzin and Lincoln (2000) illustrate a paradigm metaphorically as the net that contains the researcher's epistemological, ontological, and methodological premises. Qualitative research involves an interpretative, naturalistic approach to the world and seeks understanding.

The overall aim of the thesis, and the aim of each study, has guided the choice of method presented in the Papers. The data were collected by means of personal qualitative research interviews with close relatives of people who had been critically ill (I, IV), with people who have been critically ill themselves (II, IV) and through focus-group discussions with critical care nurses (III). In the studies presented in Papers I, III and IV the aims were to describe experiences, and in the study presented in Paper II the aim was to elucidate the meaning of the lived experience. Thus a qualitative thematic content analysis (I, III, IV) and a phenomenological hermeneutic interpretation (II) were used.

Context

The settings for the research within this doctoral thesis were the general ICUs in three hospitals located in northern Sweden, where people were admitted because of life-threatening or potentially life-threatening conditions.

Participants and procedure

The participants were chosen by means of purposive sampling. This type of sampling is often used by qualitative researchers as the aim is to contact people who can provide rich information about the issues under study (Patton, 2002; Sandelowski, 1995). The inclusion criteria were related to the aim of each study within this thesis. Characteristics of the participants are presented in Figure 1. The background information about e.g. the medical diagnosis of the critically ill people, for how long they were mechanically ventilated and stayed in the ICU came from the participants in each study (I, II, IV), and was in some cases supplemented by the information from the critical care nurse who had contacted them.

| | Participants | Numbers | Sex | Age, years |
|-----------|--|---------|---------------------|--------------------------|
| Paper I | Partners of people who had been critically ill and cared for in an ICU | 7 | Male=1 Female=6 | Median=54 Range=22-63 |
| Paper II | People who had been critically ill and who had at least one close relative who had visited them in the ICU | 10 | Male=8 Female=2 | Median=58 Range=22-73 |
| Paper III | Critical care nurses with experiences of meeting close relatives of critically ill people | 24 | Male=0 Female=24 | Median=45 Range=31-60 |
| Paper IV | People who had been critically ill and who had been on a follow-up visit in an ICU | 9 | Male=8 Female=1 | Median=63 Range=40-74 |
| | Close relatives who had been on a follow-up visit in an ICU | 9 | Male=1 Female=8 | Median=52 Range=37-64 |

Figure 1 Characteristics of the participants.

Paper I

One critical care nurse from each of the three ICUs selected, contacted and informed the potential participants. The following criteria for participation were used: to have a spouse who had been critically ill and mechanically ventilated for at least 24 hours in an ICU during the last year. Eight information letters were sent to those who were interested in participating. Seven of them answered the letters; I then contacted them personally to agree a time and place for an interview. The participants had lived in a marital relationship with the critically ill person for between 4 and 40 years (median= 29). The critically ill

people had been in the ICUs for 7-42 days and nights (median=20) and all had been on a respirator for 1-28 days and nights (median=20). The medical diagnoses for the critically ill people were postoperative aortic aneurysm, sepsis/ARDS or trauma with multiple fractures.

Paper II

I contacted the participants of the study presented in Paper I by telephone and they were requested to ask their spouses, who had been critically ill and cared for in an ICU, whether they would be interested in participating in the study. Two of the spouses had died, but the remaining five were interested in participating. The inclusion criteria were that they had all been critically ill, mechanically ventilated for at least 24 hours in an ICU, were adult and had at least one close relative who had visited them in the ICU and hospital ward. Letters with more information about the study were sent to the five people who had been invited to participate. The letters contained an inquiry as to whether they wanted to be contacted to decide a time and place for the interviews. All five answered that I could contact them.

After these interviews, we found it necessary to recruit more participants to achieve a deeper understanding of the phenomenon under study; another five participants were therefore recruited. A critical care nurse working in an ICU selected and mediated contact with five people who met the inclusion criteria, who were all interested in participating. Letters with more information about the study were also sent to these additional five people. As they all consented to be contacted, we then decided a time and place for the

interviews in accordance with their wishes. The ten participants had been on a ventilator for 1-23 days (median=14) in an ICU and had been acutely, critically ill with a medical diagnosis of sepsis, multiple trauma, or aortic aneurysm.

Paper III

The head nurses in the two ICUs selected potential participants according to the criteria and gave 25 critical care nurses, who were interested in participation, an information letter. Of these 24 agreed to participate. The criteria for participating were to be a registered nurse with specialist training in intensive care nursing, who had worked for at least two years in ICUs. The critical care nurses who participated had worked as critical care nurses for between 4 and 34 years (median=15). All of them had experience of caring for critically ill people attended by close relatives. The critical care nurses were informed about the study by myself and by the head nurse in the two ICUs. The critical care nurses were then contacted to decide a time and place to hold the focus groups discussions.

Paper IV

One critical care nurse contacted and informed those people who had been to a follow-up visit in an ICU during 2002-2006 about the study. The inclusion criteria for participation in the follow-up visit were that the person had been critically ill, on respiratory treatment for at least 24 hours, and cared for in an ICU for at least 72 hours, or to be that person's close relative. The criterion for participation in the study was to have been on that follow-up visit. Twenty-three people were offered the possibility of a follow-up visit to the ICU

with their close relatives, about six months after leaving the ICU. Fifteen people who had been critically ill came to the follow-up visits together with one or two of their close relatives. In one follow-up visit the person who had been critically ill did not participate, but his close relatives did. In all but three follow-up visits one critical care nurse and one physician from the staff participated. In the three exceptions no physicians participated. We judged that the experiences of a follow-up visit to an ICU, was a limited experience in the participants' everyday life about which to narrate, therefore, in the study presented in Paper IV we chose to contact several people to receive sufficient data for a deep analysis. Letters were sent to fifteen people who had been critically ill and to their close relatives who had attended the follow-up visits, in which they were offered the opportunity to participate in an interview about their experiences.

Eighteen people answered that they were interested in participating, nine were people who had been critically ill and nine were close relatives. The medical diagnosis for those who had been critically ill were cardiac arrest with hypothermic treatment, stroke, attempted suicide, postoperative care after aortic aneurysm, ileus or adrenal gland cancer. Close relatives' relationship to those who had been critically ill was: wife (n=4), parent (n=2, one mother and one father), personal assistant (n=1) and daughter (n=2). The information about the diagnosis was given by the formerly critically ill people and their close relatives.

Data collection

Qualitative research interviews

In the studies presented in Papers I, II, and IV a qualitative research interview was chosen for data collection. The qualitative research interview can be described as a conversation with a structure and purpose, determined by the interviewer (Kvale, 2006), where the goal is to obtain open, nuanced descriptions of various aspects of peoples' experiences and the world they live in (Kvale, 1997).

The interviews were carried out after the people who had been critically ill had left the ICU and returned home (I, III) and after the follow-up visit (IV). This is in line with Sandelowski (1991, p. 164) who states that 'a life event is not explainable while it is happening; it is only when it is over it can become the subject of narration'. Most of the interviews took place in a quiet room in the participants' homes or in a public building near their homes, in accordance with their wishes. The interviews focused on particular themes in the participants' experiences during the time when the ill person was cared for in an ICU (I, II), on what close relatives meant for them during and after their critical illness (III) and on participants' experiences of the follow-up visit (IV). I also asked them to talk about their everyday life and their life together with their close relatives during this time. Clarifying questions were used, e.g., what happened next? How did you feel then? Can you give an example (cf. Kvale, 1997, Sandelowski, 1991)? The interviews (I, II, IV) were audio-taped, lasted approximately between 30 and 120 minutes and were later transcribed verbatim.

Focus-groups discussions

In the study presented in Paper III focus-group discussions were chosen for data collection. This approach encourages multiple perceptions of a similar experience and is useful when breadth of information is sought. The interpersonal communication between participants helps to clarify similarities and differences in expressed experiences or values (Barbour & Kitzinger, 1999; Morgan, 1997). A focus group is a group discussion where the researcher is actively encouraging of, and attentive to, group interaction. In addition, in focus group discussions the topic discussed is decided by the researcher (Morgan, 1997). In the study presented in Paper III, the participants in each of the four focus groups knew each other as they worked in the same ICU. There are two conflicting opinions among authors about whether or not to use pre-existing groups, and there are pros and cons for both (Freeman, 2006; Stewart, Shamdasani & Rook, 2007).

The focus-group discussions (III) I moderated and my main supervisor took notes and provided summaries to conclude the discussions. Involving two researchers in focus-group discussions increases the amount of information that can be gathered and enhances the trustworthiness of the analysis (Kreuger & Casey, 2000). I began the focus-group discussions with a general question where the critical care nurses were asked to say how they knew who the close relatives of a critically ill person were. They were then asked to talk about situations which had been ethically difficult to handle in meetings with close relatives, about how they supported close relatives, about changes they wanted to make in

their work with close relatives, and they were also asked to give examples of good or less good meetings with close relatives.

Tapping into the topic from the participants' point of view offers an opportunity to discover new ways of thinking about the issues and also produces direct evidence about the extent of consensus and diversity within the group (Morgon, 1997). The participants were encouraged to talk to one another by commenting on each other's experiences and points of view, to promote open-ended and spontaneous discussion. In response I asked further questions for the purpose of clarification and elaboration of the critical care nurses' experiences. The focus-group discussions took place in quiet rooms at the hospitals, where it was possible to sit comfortably and where everyone could see each other. This is in accordance with Morrison and Peoples (1999) who state that the focus group should be conducted in a room free from distractions and large enough to accommodate all the participants seated in a round or oval confrontation so that each can maintain eye contact with the others. The focus group discussions lasted for about 90 minutes, were audio-taped and later transcribed verbatim. After three focus-group discussions within the same ICU, and one in a different ICU and hospital, similar experiences were discussed and I and my main supervisor then judged the data to be sufficiently rich to achieve the aim of the study.

Data analysis methods

Qualitative thematic content analysis

Historically, content analysis has journalistic roots and has evolved into a repertoire of research methods that promises to yield inferences from all kinds of verbal, pictorial, symbolic, and communicative data and has migrated into various fields, where it has led to the clarification of many methodological issues (Krippendorff, 2004).

In order to achieve the aim of the studies presented in Papers I, III and IV, a qualitative thematic content analysis were used for analysing the data. Qualitative content analysis is a method that deals with manifest as well as latent content in a text (Graneheim & Lundman, 2004). A category refers mainly to a descriptive level of content and can be seen as an expression of the manifest content of the text. Analysis of what the text is about involves an interpretation of the underlying meaning of the text, referred to as the latent content (Catanzaro, 1988). The themes can be seen as expressions of the latent content of the text (Graneheim & Lundman, 2004), as themes are threads of meanings within the categories (cf. Baxter, 1991).

According to Downe-Wamboldt (1992) the goal of qualitative content analysis is to provide knowledge and understanding of the phenomena under study. She describes a stepwise procedure that has guided me through the analysis. I started to reflect on the data during the data collection and continued while transcribing and listening to tapes of the interviews and focus-group discussions. My main supervisor and I read through each

interview (I, II, IV) and focus-group discussion (III) several times to achieve a sense of the whole. This was followed by a reading aimed at identifying meaning units, guided by the aim of the study. The resulting meaning units were then condensed and compared with each other and sorted into preliminary categories. All categories were next compared and themes, i.e. threads of meaning that appeared in category after category, were identified. We discussed the categories and the themes and reached a consensus. The analyses of the studies (I, III, IV) were both manifest and latent; the manifest content is presented primarily in the categories and the latent content in the themes. By moving back and forth between the text and the output of content analysis we provided a progressive refining of the categories (cf. Downe-Wamboldt, 1992).

Phenomenological hermeneutic interpretation

The aim of the study presented in Paper II was to elucidate the meaning of close relatives for people who have been critically ill and received care in an ICU. A phenomenological hermeneutic interpretation, inspired by the French philosopher Ricoeur (1976), and developed by Lindseth and Norberg (2004), was used for the study in order to elucidate meaning as it is lived in human experience. The method aims to elicit a deeper understanding of the meaning of people's experiences by asking what constitutes the essence of the phenomenon being studied. Hermeneutic deals with interpretation and focuses on the text's sense, what it says, and its reference, what it talks about. Hermeneutic is linked to phenomenology and phenomenology is about the lived experience of

phenomena. This meaning can become public through hermeneutic interpretation of the text (Ricoeur, 1976; Lindseth & Norberg, 2004).

According to Ricoeur (1976) one's own experience cannot become another person's experience, but something is transferred from one sphere of life to another. The experience as experienced remains private, but its sense, its meaning, becomes public. When people talk to each other, they indicate the unique thing of that they mean. This meaning is further revealed when the speech is transcribed and fixed as a text, and it is then possible to explore the meaning of the text itself (Ricoeur, 1976). The text has a semantic autonomy, which means that when the discourse is fixed as text it becomes free from the utterer's intention; instead the aim is to understand what the text is all about. If the text goes beyond the utterer's horizon it means there is a surplus of meaning within the text. Thus the text has the ability to say more and different things than were originally in the mind of the utterer (Kristensson-Uggla, 1999).

In order to become open to the experience of the participants and to the comprehensible meaning implicit in their experience, I tried to be as open-minded to the phenomenon as possible and refrain from making judgements about the factual, concentrating instead on accomplish epoché, or bracketing, by assuming from the participants' narrated lived experience. According to Lindseth and Norberg (2004) the natural attitude is an attitude in which we judge and have made judgements about the phenomenon, we state the facts and take for granted what is meant. To shift to the phenomenological attitude we must refrain

from making judgements about the factual and instead narrate from lived experience, and then consider what the essential characteristics of the expressed meaning are.

The phenomenological hermeneutical interpretation consists of three phases of interpretation; there is constantly progressing dialectic movement between the whole and the parts of the text, between understanding and explanation, and then a progression from explanation to new comprehension (Lindseth & Norberg, 2004). During the first phase of the interpretation process, the naïve understanding, my main supervisor and I read the interview text several times, as open-mindedly as possible, allowing the text to speak to us, in order to grasp its meaning as a whole. In the next phase, the structural analysis, the text was divided into meaning units, i.e. a sentence or several sentences that had a similar meaning in relation to the aim of the study. Each meaning unit was then transformed by condensation and abstraction to produce a formulated meaning. The formulated meanings were related to each other, reflected on and organized into one major theme and six sub-themes. In the third and final phase of the interpretation, we read the text again and formulated a comprehensive understanding and reflection. This was constructed based on the naïve understanding, the structural analysis, our preunderstanding and the literature.

Ethical considerations

The heads of ICUs in the northern part of Sweden were contacted and gave permission for us to perform the studies (I-IV) in the ICUs. Those who were interested in participation received a letter which provided more information and where they could decide whether

or not they wanted to participate. If they wished to do so, they were contacted about when and where the interview or focus-group discussion should be held. Informed, voluntary consent is an explicit agreement made by participants in research projects, without threat or inducement. It is based on information provided before consent to participation (Kvale, 1997).

Before starting the interviews (I, II, IV) and focus-groups discussions (III) the participants were given information about the general nature of the study and that the data would be tape recorded. The participants were reassured that their participation was voluntary, that they could withdraw from the study at any time and they were guaranteed confidentiality and an anonymous presentation of the findings. According to Kvale (2006) a qualitative research interview is not an open and dominance-free dialogue between equal partners as the interviewer sets the stage and script in accordance with their interests. The interview can awaken sad and painful memories among the participants (Dyregrov, 2004; Morse, 2000b), and the use of a tape recorder might be intimidating to some participants (Oliver, 2003). The researcher cannot be certain of the consequences for the participants, but can do as much as possible to minimize the risk of causing harm (Oliver, 2003). During the interviews and focus-group discussions I tried to make the participants feel comfortable and I noticed if the participants indicated that they were uncomfortable with the situation or needed comfort; some of them were sad and cried when they talked about touching memories and experiences, but all of them wanted to continue and complete the interviews. Being allowed to give expression to pain and confusing thoughts before

someone from the outside can be experienced as a relief and an opportunity seldom offered, but a qualitative research interview is not, and should not be described, as therapy (Dyregrov, 2004).

After the interviews (I, II, IV) and focus-group discussions (III), the participants were able to reflect on their participation and the feelings that had arisen. Wibeck (2000) emphasizes the importance of not talking about sensitive information revealed by the other participants that is discussed within the focus group, and we reminded the critical care nurses not to talk about the other critical care nurses' experiences outside the group (III). The Ethical Committee at the University (I, II, III) and the Regional Ethical Review Board (IV) approved the study.

FINDINGS

The categories, sub-themes, themes and comprehensive understanding are presented in Table 1. The findings of the four Papers are presented separately.

Table 1 Overview of the findings in Papers I-IV

| Paper | Category (I, III and IV) Sub-theme (II) | Theme (I-IV) | Comprehensive understanding (II) |
|---|---|---|--|
| I The experiences of partners of critically ill persons in an ICU | Seeing the critically ill person changed Wishing to be near Showing respect Having someone near Living a changed everyday life Being sad and afraid Knowing and not knowing Alternating between hope and despair | Being present Putting oneself in second place Living in uncertainty | |
| II Receiving power through confirmation: the meaning of close relatives for people who have been critically ill | Receiving explanations A feeling of being understood Feeling of safety Gaining strength and will-power Having possibilities Realizing their value | Experiencing confirmation | To have someone close, while and after being critically ill, who cares, who understands, who makes you feel needed and loved means to receive motivation and power to continue the struggle. |
| III Close relatives in intensive care from the perspective of critical care nurses | The voice of the critically ill person Uncertainty about who is the close relative An important and demanding part of the work Relieving the situation Keeping hope alive and being honest Being called into question Feelings of inadequacy Absence of feedback | A link to the critically ill person Getting near Wanting to do a better job | |
| IV Re-visiting the ICU. Experiences of follow-up visits to an ICU after discharge: a qualitative study | | Receiving strength from returning together Making sense of the critical-illness experience Feeling grateful to have survived The possibility of improving the care | |

Paper I: The experiences of partners of critically ill persons in an ICU

Close relatives described how it was a frightening experience when their spouse became critically ill. They felt scared and it was unreal to see the critically ill person lying in the ICU with tubes in their body. It was important for them to be near the ill person, but it was difficult to see, touch or talk to the critically ill person during respirator treatment in the ICU. Helping the ill person with their care was described as positive but at the same time close relatives felt confidence with the staff and wanted them to do most of the care giving. It was important that the ill person received personal care; close relatives brought their own things from home and mediated personal information about the ill person to the staff. Close relatives wanted to show respect for the critically ill person and therefore left the room when the person was going to be nursed or receive treatment. The close relatives felt that it was essential that the staff respected the integrity and dignity of the ill person, which they mostly did, but when they did not, for example acted without respecting the critically ill person's presence, the close relatives experienced it as terrible.

The situation of the critically ill person was always in the close relatives' minds, and they thought about how others within the family would cope with the situation. Close relatives were offered the chance to talk with an almoner or a hospital priest, but none of them felt that need. They wanted support from close friends and family members. Close relatives wanted to decide for themselves who to talk to and they needed some time to be alone. Staff who were near and present in the ICU were valuable, they provided a feeling of security; the critically ill person was under supervision and the close relatives had someone

address questions to. Talking to other close relatives in a similar situation was described as strengthening. In the ICUs the relatives' room for was appreciated, as close relatives could stay there and still be close to the critically ill person. During critical periods they wished they could spend the night near the critically ill person. The everyday life for the close relatives was changed in many ways. They seldom felt hungry and had difficulties sleeping. Close relatives felt a lack of strength to manage anything at home and when close relatives were at home they were continually prepared for a phone call from the ICU.

It was hard not knowing what the outcome would be or if the critically ill person would survive. This led to feelings of insecurity about the future of the whole family and about practical matters. Waiting a long time to receive information exacerbated the situation. Close relatives wanted the information they received to be honest and straightforward. It was frustrating to receive different information e.g. when treatment was changed without their being informed about it, or when the ill person was going to be transferred to a nursing ward without their being told the reason. Close relatives found it was harder than they imagined to cope with the situation, but they had no choice. Regardless of the prognosis for the critically ill person, close relatives hoped for recovery. Sometimes they felt the information they received was too depressing. They experienced that some of the staff were of the opinion that they did not understand the gravity of the situation, but as long as the ill person was alive they felt hope.

Visiting the staff in the ICU after the critical illness was a way to bringing the time in the ICU to an end. Afterwards the close relatives felt tired, they had not spent any time thinking about themselves. Close relatives described how they could start crying even if everything had gone well. They felt worried that something else would happen to the person who had been critically ill. Close relatives tried to look to the future and said they had come to realize the importance of the person who had been critically ill and how quickly life could change.

Paper II: Receiving power through confirmation: the meaning of close relatives for people who have been critically ill

People who had been critically ill said it was essential for close relatives to be near them in the ICU so they saw someone who was familiar. Close relatives explained where the ill person was and what had occurred, they also told them what was happening in the world outside the hospital. During their critical illness the people who had been critically ill experienced delusional memories, in which they and their close relatives were often involved. Afterwards their close relatives helped them to remember what had happened in reality.

It was described as being hard to communicate while critically ill and unable to speak because of the tube in one's throat. Close relatives tried to understand them by for instance, reading their lips. Mostly close relatives understood what they was trying to say and saw if they were in pain or felt tired. The close relatives could then communicate this

to the staff. If close relatives did not understand what they tried to say it felt awful. People who had been critically ill were aware that close relatives had been present during their illness and their presence made them feel secure. When close relatives were absent the people who had been critically ill felt alone and trapped in their beds. Happiness was described as being when close relatives arrived and when they left the people who had been critically ill longed for the next time they would come. While the people who had been critically ill felt vulnerable, worn out, ill and unable to speak they wanted only close relatives to visit them and they wanted to have them near as much as possible in order for them to feel safe.

Close relatives were described as the reason for the people who had been critically ill to continue the struggle. When close relatives were absent from the ICU those who had been critically ill felt they were losing control and could die. The thought and the presence of close relatives gave them back their will to live when they felt like giving up. They felt that their close relatives cared about them and they did not want to fail them by giving up. Close relatives were the most important people in existence for them. People who had been critically ill described close relatives' support as being of great value. They felt encouraged by close relatives to do training exercises which led to faster rehabilitation; they also facilitated the possibilities for them to return home. According to the people who had been critically ill close relatives were a prerequisite for managing to pull through the critical illness and for surviving afterwards.

People who had been critically ill described how they had days when they were in pain and felt depressed, and there were days when they could not do what they wanted. Those were the days they felt they were not easy for their close relatives to cope with. Close relatives had to give up a lot of things to be with them, and they also had to take on a greater share of the work in the home. People who had been critically ill felt they had caused their close relatives suffering through becoming critically ill and the situation of close relatives had been difficult when they had been forced to live with the uncertainty of the critically ill peoples' survival. People who had been critically ill felt an increased concern that something terrible would happen to their close relatives, and they did not know how they would do without them. The relationship between them and their close relatives had been influenced as a result of what they had gone through; they had come closer and they had become more aware of what was valuable in their lives.

Paper III: Close relatives in intensive care from the perspective of critical care nurses

The critical care nurses described close relatives as important both for the critically ill person and for the critical care nurses. They expected the critically ill person to have a close relative, and they found it trying if there was no one. Close relatives could tell them about the critically ill persons' interests, habits and normal everyday life. Information from close relatives made it possible for the critical care nurses to provide individual care for the critically ill person.

If the critically ill person was unconscious it could be difficult to know who the close relatives were and what type of information the critical care nurses could give to whom. Close relatives were an important and demanding part of the critical care nurses' work. They said it was difficult when close relatives did not seem to understand the seriousness of the situation of the critically ill person. Some critical care nurses felt that close relatives had become a more important part of their work during the last few years, while others said that close relatives had always been important.

When a close relative came to the ICU for the first time the critical care nurses tried to support them by providing information and showing that they cared. Critical care nurses wanted close relatives to feel they were important and encouraged them to sit near by, speak to and touch the critically ill person. Talking about everyday life or laughing together with close relatives was good, but they also experienced situations when they were not allowed to get near the close relatives. Critical care nurses described how they used to ask the close relatives to leave the room when the integrity of the ill person was threatened, but they found it could be good to let the close relatives stay near and participate in those aspects of the nursing that did not threaten the integrity of the ill person. The critical care nurses said that they did no problems with close relatives being present during resuscitation, even though it was hard to see their despair. They emphasized the importance of telling close relatives the truth about the situation, but at the same time they wanted the close relatives to remain hopeful. When there was no hope of recovery of the critically ill person, they comforted the close relatives by being in there.

Critical care nurses said that it was difficult to be honest when physicians had not given the close relatives enough information and when they changed the treatment of the critically ill person without explanations. It was also problematic when physicians wanted to continue the treatment and the critical care nurses did not think the critically ill person would survive. When one close relative did not want another close relative to be informed, critical care nurses felt it was unfair against the one who was not told about the situation. Critical care nurses sometimes felt that they were blamed for not giving enough information to close relatives. If the relationship between the close relative and the critical care nurse had started badly it could take a while to work things out. The critical care nurses felt that close relatives could be stressed and aggressive. Close relatives from different cultures could be problematic if there were diverging views on how to behave when a person was critically ill. Critical care nurses said that close relatives could test them by asking questions and then compare the answers with those they received from other staff members. The critical care nurses stated that close relatives were all different; some questioned everything while others felt safe with the care provided.

Critical care nurses explained that it could be difficult to take care of the critical ill person at the same time as wanting to support the close relatives. They wished that one critical care nurse could take care of close relatives and another of the critically ill person, especially when they just had arrived to the ICU and during resuscitation. Critical care nurses wanted to have an almoner or hospital priest who could have deeper discussions with close relatives. They wanted to take part in meetings where close relatives were given

information by physicians, to be able to answer the close relatives' questions about the information. The room for close relatives was small and critical care nurses were not able to offer close relatives the option of staying overnight in the ICU. The critical care nurses stated that the ICUs were not built according to the needs of close relatives. The critical care nurses wanted to discuss the goals of the care, how close relatives should be met and how they should deal with ethical questions. They had no supervision and felt they needed a forum where they could discuss with each other the given care. The critical care nurses missed feedback about what the ill person and the close relatives experienced thought about their stay in the ICU.

Paper IV: Re-visiting the ICU. Experiences of follow-up visits to an ICU after discharge: a qualitative study

It felt good to return to the ICU together to better remember what they had been told, according to those who had been critically ill and their close relatives. People who had been critically ill found it was safer to make the follow-up visit with someone who had been present in the ICU and who remembered various events, as they were a little afraid of being asked questions they might not be able to answer or not know where to go. The close relatives described the follow-up visit as a way of supporting the person who had been critically ill. They said they wanted to talk about what had happened to them after the period in the ICU, and how the person who had been critically ill behaved when he or she was not unconscious or confused.

The follow-up visit was one way of getting to know what had happened and to find out why. People who had been critically ill said that they had also spoken to their close relatives; met other people who had cared for them; returned to the place where they had been critically ill; read their personal written diary and saw photographs taken while they were critically ill. Looking at pictures and reading the diary from the time when they were critically ill was described as valuable; they got a picture of what had happened and how ill they had been. It was hard to read about how much their close relatives cared and worried about them and some cried when they read certain part of the diaries. Close relatives also appreciated the diary but found parts of it to be hard to read.

People who had been critically ill were pleased to return to the ICU when they felt their mind was clear. They said they did not remember the spatial experience of the ICU; it was only when they returned that they understood what it looked like and how the equipment worked. There were descriptions of recognizing different voices or sounds when they heard them again, and they appreciated seeing once more the specific room where they lay critically ill in the ICU and some of the equipment. People who had been critically ill had experienced hallucinations or nightmares, and they talked about this during the follow-up visit. It felt good to talk to the staff, who knew that hallucinations and nightmares during ICU treatment were common and that they had not thought the critically ill people were mad when they talked about these experiences. Hearing possible reasons for the hallucinations was described as confirmation and valuable feedback.

Close relatives said they did not have many unanswered questions; they knew what had happened when the person became critically ill, but during the follow-up visit they felt they got answers about why it happened. It was helpful for them to have this possibility, as otherwise they would have been left alone with the critically ill person's thoughts and questions about the time they spent in the ICU. Returning to the ICU revived memories from the time they had spent there, it had been a difficult time, and it felt good to return and see where the person who had been critically ill had, in a way, come back to life. Meeting the staff again was described as an important part of the follow-up visit, giving them a chance to express their appreciation of their work. Participants valued the opportunity to return to the ICU and that the nurse and the physician had taken the time to meet them. Close relatives described how they had developed a special relationship with some of the staff who were most involved in the nursing and treatment of the critically ill person and they described it was nice to meet them again.

People who had been critically ill and their close relatives said that during the follow-up visit they had been asked to suggest improvements that could be made in the care within the ICU. They mentioned various experiences that they had thought of which might could have been better, but people who had been critically ill found it difficult to suggest improvements within the nursing care as they did not clearly remember the time they spent in the ICU. It was said to be disappointing when another physician or critical care nurse, instead of the one who had mostly treated the ill person, participated in the follow-up visit. Close relatives said they had felt that the room intended for close relatives in the

ICU was too small and sometimes it had been hard to share it with others. They described the encounter with the staff during the critically ill person's stay in the ICU as good but they also mentioned examples of meetings that were not so good.

DISCUSSION

The overall aim of this doctoral thesis was to describe the experiences of close relatives within intensive care from the perspectives of close relatives (I, IV), formerly critically ill people (II, IV) and critical care nurses (III). The findings show that the close relatives wanted to be near the critically ill person and to know what was happening during their time at the ICU (I). These were absolute prerequisites for close relatives to be able to endure the drastic and rapid changes in their everyday life and to support the critically ill person (I, II). For the critically ill person the presence of close relatives gave them the power to sustain the struggle on not die (II). The critical care nurses stated that close relatives were an essential source of knowledge about the critically ill person that allowed them to provide personal nursing care (III). Formerly critically ill people and their close relatives experienced the follow-up visit to the ICU as one way of putting together the pieces of what had happened and gave them a chance to voice their opinions about the nursing care and treatment provided (IV).

Close relatives had a strong desire to be close to the critically ill person during the time in the ICU (I-IV). According to Lévinas (1974/2006) we have to assume responsibility for the other, an ethical responsibility which is a duty we cannot refuse. In relationships,

response is required from each and every one of us. The foundation for this lies in the moral obligation to answer to the other person. The close relatives wanted to protect and support the ill person by being present (I, II, IV). Presence is the most fundamental experience of reality, an elemental closeness (Younger, 1995).

By being present, giving personal information to the staff and bringing in personal things belonging to the ill person, close relatives protected and supported the ill person (I). This can be regarded as close relatives acted as an advocate. An advocate, according to Hummel (1998), is a person who seeks to redistribute power and resources to people who are in a need. In order to serve as their advocate, the close relative acted in accordance with their own opinion of the ill person's wishes and values. This is in line with Lévinas (1970/2003) who states that to suffer for the other is to serve the other; it is to provide for their specific material needs, to moderate their pain, anxieties, and fears, and to respect their freedom and dignity. Care for the other is care for the self, nothing is more significant. As they were present close relatives could tell the person who had been critically ill about what had happened from the time they had no, or only delusional memories (II, IV). This can be seen as confirmation, and was shown by close relatives being present and available to ensure that the ill person's needs were responded to appropriately and the ill person's existence was acknowledged (cf. Younger, 1995).

Close relatives felt that no one could answer their questions about the future, and the uncertainty was difficult to live with (I). The most deeply held assumption about our

everyday life is that we will continue to be alive and it is in the light of this assumption that we engage in daily activities. The onset of illness confronts one directly with one's personal vulnerability. Loss of control is central to the experience of illness, especially when the illness is serious and unexpected. This is accompanied by the awareness of the unpredictability of the familiar world because it can no longer be assumed that things will continue as they have in the past (Toombs, 1993).

The anxiety that close relatives experienced with regard to the critical ill person severely affected their everyday life and caused them suffering (I). Younger (1995) states that suffering occurs when the meaning of the pain is very serious or the person feels out of control. Suffering brings us closer to our own existence by allowing us to consider what life means. Close relatives and formerly critically ill people searched for an answer to why the critically illness had stricken the ill person (IV). Eriksson (2006) suggests that to trying to see a meaning in one's suffering and feeling that there is an answer to the question why is one way for a person to confirm his or her self-worth. Not knowing about the outcome of the ill person was the most difficult aspect for close relatives to manage (I). According to Lévinas (1974/2006) we are hostages in our relationships to the other; worrying about the other can become such a powerful all consuming emotion that it imprisons the worrier. This indicates that ICU staff must provide answers to those questions that can be answered, but they also need to be with the close relatives when they have questions about why the person is critically ill, the meaning of it all and what the future will hold.

There were situations when close relatives lacked explanations, for example when the treatment of the ill person was changed without their knowing the reason (I, III). Close relatives not being given explanations and thus feeling that they were not seen may be compared with what Younger (1995) describes as alienation. This is a form of dissatisfaction resulting from one's perceived association with a person or group. The experience of alienation involves being in a disadvantaged position, and feeling meaninglessness, helplessness, incomprehensibility and loss of community.

Critical care nurses talked about giving the close relatives information (III), while close relatives said they wanted to know things, to receive knowledge, about what had happened and why (I, IV). It is necessary to receive knowledge, more than information. The difference between information and knowledge is that information concerns primarily the communication of facts, whereas knowledge comprises a body of learned facts. Having knowledge is an important aspect of being a part of what is happening, but there are necessary prerequisites for comprehending the information (Eldh, 2006). Close relatives wanted to know what to expect and the truth from the beginning (I). The information close relatives receive, is interpreted from their own perspective and they might need clarification about how to interpret it (Verhaeghe, van Zuuren, Deefloor, Duijnste & Grypdonck, 2007).

Close relatives found it frustrating to receive different instructions (I), while critical care nurses found it difficult when close relatives asked questions and then compared the

answers with those they had received from other personnel (III). Hughes et al. (2005) found that staff felt that close relatives played one critical care nurse against another, whereas close relatives felt the only reason they repeatedly asked various questions was because they received inconsistent information. Close relatives were not always understood by those who had not taken part of their entire experience (I, III). What they experience is not the same as what another experience as they are not the other (Lévinas, 1979/1992). This shows the importance of basing communication on a shared understanding, where the close relative and the critical care nurse understand and are understood by each other. Ricoeur (1976) stated that mutual understanding relies on sharing the same sphere of meaning. By being a part of each other's world a connectedness can be created, achieved by the staff's awareness, wisdom, care, involvement and commitment of the close relative (Younger, 1995).

When the close relatives received the knowledge they asked for they felt that the staff were honest and felt safe (I), which is very important when close relatives are waiting for an answer about the outcome for the ill person (Wilkes, White & O'Riordan, 2000). Close relatives felt that some of the staff thought that the close relatives did not understand the gravity of the situation, hoping that the ill person would survive (I, III). Not feeling any hope of recovery was difficult (I). The most intensive and powerful level of hope is to see a meaning in loss or suffering (Cutcliffe & Herth, 2002). False hope is based on lack of knowledge and thus hoping for the impossible, which is more painful than hoping for something improbable that is not happening (Verhaeghe et al., 2007). Regardless of the

prognosis for the critically ill person, close relatives hoped they would recover, and this hope seemed to give them the strength to endure the suffering. Their hope was evinced with the wellbeing of the critically ill person (I, III). For the critically ill people close relatives provided motivation to continue the struggle (II). Hope can either be hoping for something, for example that the ill person will recover, or to be living in hope, which means reconciliation and comfort in the face of life and death (Benzein, Norberg & Saveman, 2001).

Critical care nurses stated that the ICUs were not built to accommodate the needs of close relatives (III, IV), and close relatives felt it was hard to share the small relatives room with others (IV). However, the most important thing for close relatives was the possibility of being close to the ill person and they felt they would have liked the chance to sleep near the critically ill person (I). Relatives' rooms that are comfortable and close to the critically ill person can alleviate the difficulties of waiting (Kutash & Northrop, 2007). Lévinas (1974/2006) maintains that we are chosen to put the other before ourselves, and thus, close relatives focused on the person who was ill, and this became more important to them than the nature of the physical environment (I, II). To be human is to care for the other above oneself, which Lévinas (1970/2003) calls the wisdom of love; providing for the other what you would have wanted yourself.

Participating in the care of the ill person was described as positive; it felt good for close relatives to have a task and at the same time to be near the ill person (I, II). Critical care

nurses stated they could be better at inviting them to participate in the care of the ill person (III). According to Elredge (2004) close relatives want to participate in the nursing care because it gives them an opportunity to respond to the ill person's need for comfort. In this matter personal choice is essential. Hammond (1995) shows that both close relatives and critical care nurses think it to be improper for close relatives to take part in nursing care that could be sensitive or embarrassing for the ill person. That is in accordance with the findings of this thesis, where close relatives preferred to leave the room when e.g. the personal hygiene of the ill person was being attended to, as protecting the dignity of the ill person was important (I- IV). It was important for close relatives to respect the ill person by not exposing their body and showing them respect through their behaviour (I, IV); this exemplifies how the other's dignity can be confirmed (Edlund, 2002).

Staff who acted as if the critically ill person could hear were appreciated by close relatives (I). The opposite situation was, however, also experienced; i.e. staff that talked and acted without respecting the presence of either the critically ill person or the close relative. This was felt to be awful (I, IV). If close relatives had an upsetting relationship with only one of the staff in the ICU this seems to over-shadow other positive connections with others (Eggenberger & Nelms, 2007). When someone causes the close relative and the critically ill person suffering, it implies their violation. This is, according to Eriksson (2006), a failure to confirm the worth of the others, which also simultaneously violates the dignity of the person who is causing their suffering. To be treated with dignity is to be treated with

respect, to be considered worthy of the regards of others; to lose one's dignity is to feel that one's value as a person is irreparably diminished (Toombs, 2004).

It was especially important to safeguard the dignity of the critically ill person, according to the close relatives, as the ill person could not defend it him or her self (I, II). Close relatives appreciated it when staff were able to meet the person who had been critically ill so they could see who the person was when they were not unconscious or confused (IV). The close relatives showed the ability to put themselves in the other's place allowing them to feel sensitivity, compassion, and an understanding of the vulnerability and suffering of the other (I, II, IV). This is an unsurpassable moral responsibility we have to, and for, the other person (Lévinas, 1970/2003). When the dignity of the critically ill person was violated, the close relative was personally affected (I, IV). This aroused strong emotional responses in them and summoned them to defend the ill person. The meaning of dignity is experienced when the staff are attentive to perceive the ethical injunction of the critically ill person, and of their close relatives, so that close relative can feel that the staff are doing what is right and good (cf. Söderberg, Gilje & Norberg, 1997).

METHODOLOGICAL CONSIDERATIONS

In qualitative research estimating the number of participants required depends on the scope of the study, the nature of the topic, the study design and the quality of the data (Morse, 2000a). When determining the sample size (I-IV) we judged the quality of the data collected against the specific aim, research method and the intended research product. It

should achieve variation of experiences and permit a deep analysis of the data (cf. Sandelowski, 1995). The participants gave rich descriptions of their experiences about the topic under study (I-IV). This means that they gave detailed information about the phenomenon under study. They were willing and able to examine their experience of the situation, and to share it with us (cf. Morse, 1991).

There was some differences in the participants' ages, and the diagnose of the formerly critically ill people (I, II, IV). This could have influenced the findings; nevertheless the participants' experiences were quite similar. The participants from the study presented in Paper II were interviewed about one and half years after their stay in the ICU, as the aim was to describe the meaning of close relatives for people who had been critically ill, during and after their stay in the ICU. According to Lof, Berggren and Ahlström (in press) formerly critically ill people's memories of unpleasant emotions from their stay in the ICU are less intense after 12 months than after three months, and after 12 months they have greater recall concerning caring physicians, critical care nurses and close relatives. Judging from this the optimal time to interview formerly critically ill people is open to discussion.

In order to achieve a truthful interpretation of the text the process of interpretation must be strict. This has guided the work with the analyses and interpretation of data in this thesis. We understand in relation to our preunderstanding and our preunderstanding gives us a horizon to engage with the horizon with the text (Geanellos, 2000). The horizon is the range of vision that includes everything that can be seen from a vantage point. To have

a horizon means not being limited on what is nearby but being able to see beyond it (Gadamer, 1994). While interpreting a text we revise our preunderstanding and it may be necessary to broaden it by studying relevant literature, as insufficient preunderstanding prevents the grasping of essential meanings in the text (Lindseth & Norberg, 2004). It is important to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own fore-meanings, because preunderstanding lead to errors when the researchers are not sensitive to the text's alterity and ignore the actual meaning of the text if it is not what they imagine it to be (Gadamer, 1994). We have discussed the findings (I-IV) with other colleagues to prevent premature conclusions of the findings and to prevent our pre-understanding prejudicing the interpretation. Peer debriefing take place in different ways, for example the emerging findings can be discussed at intervals with knowledgeable colleagues (Long & Johnson, 2000). The interpretations were checked, discussed and refined by us authors to improve their trustworthiness.

In phenomenological hermeneutic research (II) the text speaks of a possible world, the dimensions of which are opened up and revealed by the text. There is always more than one way of construing a text, but all interpretations are not equal. It is always possible to argue for or against an interpretation (Ricoeur, 1976, 1993). The findings presented in Paper II are based on the most probable interpretation we could achieve, but arguments can be made for and against it.

In the study described in Paper III, I and my main supervisor met the participants for a second time where the findings were presented to and discussed with them. This is described as member-check and, according to Lincoln and Guba (1985), is the most crucial technique for establishing credibility. The main reason for member checking was to get feedback from the participants on our interpretation of the data (III). The findings agreed with the participants' experiences, even though they did not recognize all the individual examples (III). There may be a risk involved in member-check, as study results are synthesized and de-contextualized from the individual participants, which can make it difficult for the participants to recognize themselves and their particular experiences (Morse, Barrett, Mayan, Olsson & Spiers, 2002).

My ambition has been to present the procedure, context and the findings as exactly as possible, and I have been consistently aware of the importance of ensuring rigour. In order to help the reader to determine the level of trustworthiness and transferability of a study it is important to present the procedure, context and findings as accurately as possible (Lincoln & Guba, 1985), as the trustworthiness of the analysis is related to the extent to which the reader finds the interpretation adequate as well as logical (Whittemore, Chase & Mandle, 2001). I have proceeded throughout the work with this doctoral thesis in that spirit.

CONCLUDING REMARKS

People, when healthy, who have a close relationship with each other are a naturally part of each other's everyday lives. When someone becomes acutely, critically ill the close relative's need to be that part of the other's, the ill person's, everyday life, remains. This was shown in this thesis by the close relatives' wish to be near, to support and protect the critically ill person and by their absolute need longing to know what was happening. Formerly critically ill people said that they wanted to have their close relatives close by as much as possible to during and after they were stricken by the critical illness. To them, close relatives provided strength and will-power and were the most important people. Loneliness and fear were experienced in the absence of close relatives, and in order to feel safe, they wanted their close relatives to stay near them. Close relatives are dependent on the goodwill of the staff to allow and facilitate their being close to the ill person. Critical care nurses know how the situation of close relatives could be improved when someone close becomes critically ill and is cared for in the ICU, but by whom should such improvements be made?

CLINICAL IMPLICATIONS

From the findings within this thesis, some clinical changes could be made that would increase the close relatives' possibilities for to be near to the critically ill person and a part of their dramatically changed everyday life. By regularly receiving clear and honest information in a way that makes it possible for them to understand and know about what was happening, while still retaining a realistic hope, close relatives could be given the

opportunity to ask their questions. Close relatives need to get answers to the questions that can be answered, but also to discuss questions that is hard to answer. By making it easy for them to be near the critically ill person, close relatives can provide the support the ill person wants to have, and the close relatives want to give. This can be done by extending the possibilities for close relatives to remain close to the critically ill person, both day and night, in the ICU. Close relatives could for example, be offered the chance to rest or sleep close to the ill person, to get food and something to drink, access to comfortable and spacious room close to the critically ill person and an environment that allows them to be with the ill person and welcomes their presence.

When close relatives are near to the critically ill person, critical care nurses can learn to know more about the latter, and thus give nursing care and treatment that accord with their values and wishes. In a relationship where the situation of close relatives is fully understood by the critical care nurse, and by other staff within the ICU, the possibility that their needs will be met probably increases. A shared understanding of close relatives' situation is thus a necessity. Close relatives, and critical care nurses, also need to be aware of and involved in the goals of the treatment given to the critically ill person, especially if the goals and treatments are changed.

The dignity of the critically ill person, and thus also that of the close relatives, must always be maintained. This, I suggest, can be achieved through the knowledge and reflections of the staff concerning what dignity means for this particular person and what it means in

general. Violation of the dignity of another person must never be accepted. As a follow-up visit to the ICU, and a personal written diary, were experienced as being valuable, I therefore recommend that more people are given these possibilities. The close relative and the ill person must be afforded the prerequisites to be essential part of each other's everyday lives, especially when critical illness strikes.

SUMMARY IN SWEDISH - SVENSK SAMMANFATTNING

En önskan om att vara nära: Upplevelsen av närstående inom intensivvård från närståendes, tidigare svårt sjuka personers och intensivvårdssjuksköterskors perspektiv

Introduktion

Denna doktorsavhandling fokuserar på närstående till svårt sjuka personer som vårdas eller har vårdats på en intensivvårdsavdelning (IVA). Fyra delstudier ingår och refereras till i texten med hjälp av de romerska siffrorna I-IV. Avhandlingen har en kvalitativ design och det övergripande syftet var att beskriva upplevelsen av närstående inom intensivvård från närståendes (I, IV), tidigare svårt sjuka personers (II, IV) och intensivvårdssjuksköterskors perspektiv (III). När en person blir akut, svårt sjuk så drabbas även den sjuke personens närstående. En närstående till en svårt sjuk person är någon som bryr sig om personen som är sjuk och som den sjuke litar på. Den närstående kan vara en familjemedlem, make eller make, partner eller en vän.

Från det övergripande syftet formulerades ett specifikt syfte för respektive delstudie enligt följande; att beskriva närståendes upplevelser när deras make/maka/sambo var svårt sjuk och vårdades på en intensivvårdsavdelning (I), att belysa innebörden av närstående för personer som varit svårt sjuka och vårdats på en intensivvårdsavdelning (II), att beskriva intensivvårdssjuksköterskors upplevelser av närstående inom intensivvård (III), och att

beskriva upplevelsen av ett återbesök på en intensivvårdsavdelning för personer som vårdats där och deras närstående (IV).

Rational för avhandlingen

Det finns endast begränsat med forskning som beskriver upplevelsen av akut, svår sjukdom från de närståendes perspektiv och den forskning som finns är framför allt kvantitativ.

Kunskap om vad närstående till personer som är eller varit svårt sjuka tvingas gå igenom är utgångspunkten för att kunna hjälpa dem. För att uppnå denna kunskap kommer upplevelsen av närstående till personer som är eller varit svårt sjuka beskrivas från tre perspektiv; från närståendes perspektiv (I, IV), från perspektivet av personer som varit svårt sjuka (II, IV) och från intensivvårdssjuksköterskors perspektiv (III). En ökad kunskap om närstående och upplevelsen av dem från dessa perspektiv ger en möjlighet att förbättra och förändra omvårdnaden inom intensivvård så att den svarar mot närståendes behov.

Deltagare och metod

Delstudierna har genomförts vid tre intensivvårdsavdelningar i norra delen av Sverige.

Urvalet av deltagarna gjordes ändamålsenligt; de som tillfrågades hade erfarenhet som svarade mot syftet i respektive delstudie. I delstudie I intervjuades sju personer som var make/maka/sambo till en person som varit svårt sjuk och vårdats med respiratorbehandling minst ett dygn på en IVA. Det var en man och sex kvinnor i åldrarna 22-63 år som deltog.

I delstudie II intervjuades tio personer som varit svårt sjuka och vårdats på en intensivvårdsavdelning och som hade minst en närstående. Fem av dessa personer var de

som var svårt sjuka i delstudie I och ytterligare fem deltagare rekryterades via en intensivvårdsavdelning. Av deltagarna var två män och åtta kvinnor och de var 22-73 år. Deltagarna hade respiratorbehandlats under minst ett dygn och vårdats akut, svårt sjuka på en IVA. I delstudie III genomfördes fokusgruppsdiskussioner i fyra olika grupper vid två olika sjukhus med totalt 24 intensivvårdssjuksköterskor, samtliga var kvinnor i åldrarna 31-60 år med erfarenhet som intensivvårdssjuksköterska i 4-34 år.

I delstudie IV intervjuades 18 personer som varit på ett återbesök på en intensivvårdsavdelning, nio av dessa personer hade vårdats där då de varit svårt sjuka och de resterande nio personerna som deltog var deras närstående (IV). Av dem som deltog och som hade varit svårt sjuka var åtta män och en kvinna och de var 40-74 år. Samtliga hade respiratorbehandlats under minst ett dygn och de hade vårdats på en IVA på grund av akut, svår sjukdom. De närstående som deltog var en man och åtta kvinnor. De var 37-64 år och deras relation till personen som varit svårt sjuk var att de var hustru, mamma, pappa, personlig assistent eller dotter till personen som vårdats på IVA.

Deltagarna i de fyra delstudierna ombads att berätta om sina upplevelser relaterade till syftet i respektive delstudie och klagörande frågor ställdes. Intervjuerna (I, II, IV) och fokusgruppsdiskussionerna (III) spelades in på band och skrevs därefter ut ordagrant. De utskrivna texterna analyserades med en kvalitativ tematisk innehållsanalys (I, III, IV) och med en fenomenologisk hermeneutisk metod (II).

Resultat

Delstudie I

Resultatet visar att det som var det viktigast för närstående var att få vara nära den sjuke personen. Samtidigt som det kändes skrämmande och överkligt att se personen som var svårt sjuk med slangar i sin kropp under pågående respiratorbehandling. Närstående beskrev att de ville hjälpa den sjuke personen med olika saker. De kände respekt för den sjuke personen och det var viktigt att personalen visade respekt och behandlade den sjuke personen med värdighet. När närstående önskade någon att prata med så vände de sig i första hand till en nära vän eller familjemedlem. Närstående uppskattade att ha personal nära då personen som var sjuk fick ständig tillsyn och samtidigt kände närstående stöd genom personalens ständiga närvaro.

Närstående ville att personen som var sjuk hade det så bra som möjligt och deras dagliga liv var fokuserat på av detta. Tankarna var hos personen som var sjuk, men de tänkte även på övriga familjemedlemmar. De hade varken kraft eller motivation till att göra någonting annat. Detta kan ses som naturlig kärlek och ett etiskt krav att ta vara på den andre personens liv på det sätt som gagnar personen bäst. Genom att visa omtanke till personen som var sjuk, kunde välbefinnandet för den sjuke personen öka, men även för de närstående.

Närstående uttryckte en stark oro över hur framtiden skulle bli. Framst för hur det skulle gå för personen som var sjuk, men också för hela familjen och med praktiska saker. Det

svåraste var att tvingas vänta på besked och att inte veta om personen skulle överleva. Att få ärliga och raka besked var viktigt. Närstående som hade fått vänta länge på information menade att detta hade försvårat situationen ytterligare. De beskrev att de kände sig upprörda över ändrade ordinationer och att olika bud gavs utan att de fick veta varför. De kunde känna att personal ansåg att de inte förstod hur kritiskt det var. Oavsett prognosen för personen som var sjuk så fanns dock hoppet hos närstående om att det skulle gå bra. Att känna hopp, även utan garantier för framtiden, är också att kunna se en mening med det som händer. Även om ingen kunde svara exakt på hur framtiden skulle bli så ville närstående förstå och de ville få behålla hopp för att kunna uthärda denna svåra situation.

Delstudie II

De närstående var framför allt en person som var extra betydelsefull för personerna som varit svårt sjuka. För nio av deltagarna var det deras make/maka/sambo och för en deltagare var det hans mamma. Dessutom beskrev de att även deras barn, föräldrar och syskon stod dem nära och det var deras närvaro de önskade under och efter tiden på IVA. Personerna som varit svårt sjuka beskrev att det var nödvändigt att de närstående fanns nära dem på IVA så att de kunde se någon som de kände igen. De närstående förklarade för dem vart de var och vad som hade hänt och de berättade om vad som hände i världen utanför sjukhuset. Det var svårt att kunna kommunicera med en tub i halsen. De närstående försökte förstå vad de svårt sjuka försökte säga och de gjorde det för det mesta, men de gånger som ingen förstod beskrevs som hemska. Personerna som varit svårt sjuka var medvetna om att de närstående var hos dem under tiden på IVA och deras närvaro

gjorde att de kände sig trygga. När de närstående inte var där kände de sig ensamma och fångade i sina sängar. De längtade till nästa när de närstående skulle komma och beskrev den glädje som de kände när de närstående dök upp. Under tiden på IVA då personerna var svårt sjuka och kände sig sårbara och inte kunde prata så ville de inte ha några andra besök än från sina närstående.

De närstående beskrevs som anledningen till att fortsätta kämpa. Tanken på och närvaron av närstående gav dem tillbaka viljan att leva när de kände att de höll på att ge upp.

Personerna som varit svårt sjuka kände att deras närstående brydde sig om dem och de ville inte svika dem genom att ge upp, då de var de viktigaste personerna som existerade för dem. Det stöd som de närstående gav var av stort värde. Personerna som varit svårt sjuka beskrev att de närstående var en förutsättning för dem att klara sig igenom den svåra sjukdomen och de möjliggjorde för dem att komma hem.

Personerna som varit svårt sjuka beskrev hur de hade dagar då de hade ont och kände sig deprimerade. De närstående tvingades avstå från olika saker för att vara med de sjuka personerna och de tvingades till att göra mer av det arbete som skulle göras hemma.

Personerna som varit svårt sjuka kände att de orsakade sina närstående lidanden genom att bli svårt sjuka. De visste inte hur de skulle klara sig utan dem och kände en ökad för att något hemskt skulle hända dem. Förhållandet till de närstående hade påverkats av det som de gått igenom tillsammans, de hade kommit närmare varandra och blivit mer medvetna om vad som var viktigt i deras liv. Detta tolkades som att genom bekräftelsen som de

närstående förmedlade så fick personerna som var svårt sjuka en kraft att orka fortsätta kämpa för att leva.

Delstudie III

Intensivvårdssjuksköterskorna beskrev att de närstående var viktiga för både den sjuke personen och personalen och det kändes frustrerande för dem om det inte fanns några närstående. De närstående gav en bild av den sjuke personens dagliga liv, intressen och vanor, vilket gjorde att intensivvårdssjuksköterskorna kunde ge en personlig omvårdnad. De beskrev situationer när det var svårt att avgöra vem som var den sjukes närstående. De närstående upplevdes som en viktig och samtidigt krävande del av deras arbete.

Intensivvårdssjuksköterskorna beskrev att de viktigaste sätten för dem att stödja närstående var genom att vara nära, lyhörda och visa att de brydde sig om dem.

Intensivvårdssjuksköterskorna bad de närstående lämna rummet när integriteten för den svårt sjuke var hotad. Samtidigt som det var naturligt att de närstående kunde delta i av andra delar av omvårdnaden. Intensivvårdssjuksköterskorna betonade vikten av att vara ärliga om hur allvarlig situationen för den sjuke personen var, samtidigt som närstående skulle få ha kvar något slags hopp. De beskrev situationer när det kunde vara svårt att vara trovärdig mot närstående exempelvis om behandlingen av den sjuke ändrats utan förklaring eller de inte fått tillräcklig information. Intensivvårdssjuksköterskorna beskrev att de närstående ibland anklagade personalen för att inte ge tillräckligt med information.

Vissa närstående kunde vara kritiska, stressade och aggressiva. Om relationen mellan intensivvårdssjuksköterskorna och de närstående hade börjat dåligt kunde det ta ett tag att reda ut. De närstående kunde testa intensivvårdssjuksköterskorna och jämföra svaren de fått av annan personal eller jämföra vården mellan olika sjukhus. Intensivvårdssjuksköterskorna diskuterade hur olika de närstående kunde vara, några närstående ifrågasatte allt medan andra var trygga och säkra på att allt gjordes för den sjuke personen. Förhållanden som bygger på en ömsesidig förståelse kräver både tid och energi, men är av stor betydelse för både närstående och intensivvårdssjuksköterskor. Detta var något som intensivvårdssjuksköterskorna arbetade för att uppnå och kan ses en förbättring av omvårdanden inom intensivvård. De beskrev även andra förbättringar som kunde göras i deras arbete, förändringar som skulle gynna både närstående till svårt sjuka personer som vårdas på IVA och dem själva.

Delstudie IV

För personerna som varit svårt sjuka kändes det tryggt att gå på återbesöket tillsammans med någon som varit närvarande på IVA och som mindes olika händelser. De närstående beskrev att återbesöket var ett sätt att stödja personen som varit svårt sjuk. De ville prata om vad som hänt dem efter tiden på IVA och hur personen som varit svårt sjuk var när han eller hon inte var medvetslös eller förvirrad.

Återbesöket var ett sätt att kunna få veta vad som hänt och varför då den sjuke personen vårdades på IVA. Att se fotografier och läsa dagboken från tiden på IVA beskrevs som

värdefullt; de som varit sjuka fick en bild av vad som hänt och hur allvarligt det varit. Det var svårt att läsa om hur mycket deras närstående brydde sig om dem och oroade sig för dem, några grät när de läste speciella delar av dagboken. De närstående uppskattade också dagboken, men beskrev att vissa delar var krävande att läsa.

Personerna som varit svårt sjuka kom inte ihåg den rumsliga utformningen på IVA, det var först när de återvände som de förstod hur det såg ut och hur utrustningen fungerade. De beskrev att de kände igen olika röster och ljud när de hörde dem igen. Att åter igen få se det speciella rum som de vårdades i när de var svårt sjuka och att få se en del av utrustningen uppskattades. De hade upplevt hallucinationer eller mardrömmar och pratade om detta under återbesöket. Det kändes bra att få prata med personal som visste att detta var vanligt förekommande och att få höra om tänkbara orsaker. De närstående hade inte många obesvarade frågor, de visste vad som hände när personen blev svårt sjuk, men under återbesöket fick de svar på varför det hände. Utan återbesöket hade de varit ensamma med den tidigare svårt sjuke personens tankar och frågor från den tid de vistats på IVA. Att återvända till intensivvårdsavdelningen hade väckt upp minnen från den tid de tillbringat där. Det hade varit en svår tid och det kändes bra att få komma tillbaka och se vart personen som varit svårt sjuk på sätt och vis kommit tillbaka till livet. Det uppskattades att personalen tagit sig tid att träffa dem.

De närstående beskrev att de hade utvecklat ett speciellt förhållande till några av personalen som hade varit mest involverade i vården av den svårt sjuke personen och det var trevligt

att få träffa dem igen och kunna uttrycka sin tacksamhet över deras arbete. Personerna som varit svårt sjuka och deras närstående sa att de under återbesöket blivit uppmanade att föreslå förbättringar som kunde göras inom intensivvården. De nämnde några händelser som kanske kunde ha varit bättre, men personerna som varit svårt sjuka beskrev att det var svårt ge några förslag då det inte tydligt mindes den tid de vårdats på IVA.

Avslutande reflektion

Människor som är friska och har ett nära förhållande med varandra är på ett naturligt sätt en del av varandras dagliga liv. När någon insjuknar akut och svårt så kvarstår närståendes behov av att vara en del av den andres, den sjuke personens, dagliga liv. Detta visade sig i denna avhandling genom närståendes önskan att vara nära för att skydda och stödja den svårt sjuke personen och genom närståendes önskan om att få veta vad som hände.

Personer som varit svårt sjuka beskrev att de ville ha sina närstående hos sig så mycket som möjligt under och efter tiden de var svårt sjuka. Närstående gav dem motivation till att fortsätta kämpa och de var de viktigaste människor som existerade. För att kunna vara nära den svårt sjuke personen så var närstående beroende av personalens goda vilja att tillåta och underlätta närheten mellan den sjuke personen och dennes närstående. Det framkommer i resultatet att intensivvårdssjuksköterskor vet hur de skulle vilja förbättra de närståendes situation när någon blir svårt sjuk och vårdas på IVA. Frågan är därför hur det ska bli möjligt att genomföra detta förbättringsarbete?

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Paper I



ORIGINAL ARTICLE

The experiences of partners of critically ill persons in an intensive care unit

Åsa Engström*, Siv Söderberg

Division of Nursing, Department of Health Science, Luleå University of Technology, Hedenbrovägen, SE-96136 Boden, Luleå, Sweden

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KEYWORDS

Intensive care;
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Hope

Summary The aim of this study was to describe partners' experiences when their spouses received care in an intensive care unit (ICU). Seven partners were interviewed using a narrative approach. The interview texts were subjected to qualitative thematic content analysis. The analysis resulted in three themes; being present, putting oneself in second place and living in uncertainty. It was a shocking experience for the partners to see their critically ill spouse in the ICU. It was important to be able to be present; nothing else mattered. Showing respect, confirming the integrity and dignity of their critically ill spouse were also essential for partners. Receiving support from family and friends was important, as were understanding and accepting what had happened, obtaining information and the way in which this was given. The state of uncertainty concerning the outcome for the critically ill person was difficult to cope with. The partners wanted to hope, even though the prognosis was poor.

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Introduction

Someone affected by an acute, severe illness needs care in an intensive care unit (ICU). This event changes the lives of both the person who is critically ill and of close relatives in many ways. Being the close relative of a person who is acutely, critically ill in an ICU implies an uncertainty about the future that induces high levels of stress which in turn can influence the health of close relatives (Van Horn and Tesh, 2000). Studies (Peel, 2003; Tarkka et al., 2003) have shown that close relatives are often the most important support for patients in ICU. Bergbom and Askwall (2000) demonstrated that suffering from critical illness resulted in threats to

the person in form of feelings of estrangement and fear. Close relatives could neutralise the threat by being present and also help to maintain the patient's individuality.

According to Granberg et al. (1998) close relatives greatly improved the critically ill patients' comfort as they gave them a feeling of being in contact with something real. In a grounded theory study the author found that ICU patients' need to feel safe was influenced by family and friends (Hupcey, 2000). This is in agreement with Arslanian-Engoren and Scott (2003), Hafsteindóttir (1996), McKinley et al. (2002) and Parker (1999), who noted that the presence of close relatives gave the critically ill patient a feeling of protection in a situation where they felt powerless, insecure and exposed. All these studies demonstrated the importance of close relatives for the critically ill patient.

Holden et al. (2002) in a literature review have showed that the majority of studies about the

*Corresponding author. Tel.: +46 921 75875;

fax: +46 921 75850.

E-mail address: Asa.Engstrom@ltu.se (Å. Engström).

families of intensive care patients have concentrated on their needs. Many of these studies have adopted a quantitative approach using the Critical Care Family Needs Inventory (CCFNI). The CCFNI is a Likert scale developed by Molter (1979) and has been used where the aim was to identify and rank the needs of critical care families (e.g. Azoulay et al., 2001; Bernstein, 1990; Bouman, 1984; Chartier and Coutu-Wakulczyk, 1989; Daley, 1984; Daly et al., 1994; Davis-Martin, 1994; Engli and Kirsivali-Farmer, 1993; Hunsucker et al., 1999; Leske, 1986; Lopez-Fagin, 1995; Lorentz, 1995; Mathis, 1984; McIvor and Thompson, 1988; Mendonca and Warren, 1998; Miracle and Hovekamp, 1994; Molter, 1979; Norris and Grove, 1986; Rukholm et al., 1991; Takman and Severinsson, 2004; Warren, 1993). The needs to feel hope and to obtain information were important among close relatives according to all these studies. According to Holden et al. (2002) however, studies that use the CCFNI fail to show the importance of interactions between the staff and families.

Methodological triangulation formed the basis for Burr's study (1998) which aimed to determine the degree of confirmation between family members who responded to the CCFNI and those who participated in qualitative interviews. The study found many areas of convergence between the two samples, but also areas of divergence. The need of family members to protect and provide support for the patient emerged from the interviews but not from the CCFNI. The study demonstrated family members needed to feel hope, either that the patient would survive or would die peacefully and with dignity. They wanted to support and simply be beside the critically ill patient, but mostly they felt helpless. It was also found that not knowing was the worst part for the family members. Several other studies (Bond et al., 2003; Burr, 2001; Holden et al., 2002; Jamerison et al., 1996; Kleiber et al., 1994; Kosco and Warren, 2000; Norton et al., 2003; Twibell, 1998) have demonstrated that relatives of patients who are critically ill are distressed when they do not receive sufficient information about their relatives' condition and prognosis. However, the literature review demonstrates that there is a lack of studies about the experiences of close relatives within the context of daily life from an insider view. The partner is one of the most helpful persons for critically ill patients (Hupcey, 2001) and it is the couple, not just the patient that will go through the critical illness (McCausland Kurz, 2001). In this study partners are defined as the spouse or the person whom the patient has chosen to share their life with. The critically ill patient is named the critically ill person, spouse and husband/wife relate to the partner.

Thus, the aim of this study was to describe partners' experiences when their critically ill spouse was receiving care in an ICU.

Adding to the knowledge in this area will help in the development of nursing to better meet the needs of the close relatives, especially for the partners. The research question explored was: What are the partners' experiences when their critically ill spouse is being cared for in an ICU? Insights can be gained into the close relatives' experiences, their discomfort and their needs and qualitative research can show how care can be improved and these needs met (Morse, 2000a). This study is part of a qualitative inquiry into close relatives in the context of an ICU.

Methods

A qualitative method was chosen for the study as the aim was to describe the experience of partners from an insider view when their critically ill spouse was in an ICU. In order to achieve this aim, data were collected by means of qualitative research interviews (Kvale, 1997), which were subjected to a thematic content analysis (Baxter, 1991; Woods and Catanzaro, 1988).

Participants and procedure

A purposive sample of seven partners (one man and six women) of people who had been cared for in an ICU in the northern part of Sweden participated in the study. The following criteria were used to select these participants: the participant had a spouse who had been critically ill and had been mechanically ventilated for 24 h or longer in an ICU during the last year. The partners who chose to participate were married or co-habiting with the person who was critically ill. They were aged between 22 and 63 years ($md = 54$) and had lived with the critically ill person for between 4 and 40 years ($md = 29$). The critically ill person had been in the ICU for 7–42 days ($md = 20$) and had been on a respirator for 1–28 days ($md = 20$). The medical diagnosis for the critically ill persons were postoperative aortic aneurysm repair ($n = 3$), sepsis/ARDS ($n = 3$) and trauma with multiple fractures ($n = 1$). One of the critically ill persons died in the ICU, one was still in hospital and the rest had returned home at the time of the interviews.

The heads for four ICUs in the northern part of Sweden gave their permission for the study to be performed. One nurse from each ICU selected and mediated the contact with partners who fulfilled the criteria and were interested in participating.

The partners interested in participating were informed by letter and, before the interviews started, about the general nature of the study. Letters were sent to eight partners, seven agreed to participate in the study. Data were judged to be saturated after seven interviews as no new information appeared and it was considered that there were data sufficiently large for a deep analysis (Sandelowski, 1995a). The participants were contacted by phone and appointments for the interviews were made. They were reassured that their participation was entirely voluntary and that they could withdraw from the study at any time. The participants were guaranteed confidentiality and anonymity in the presentation of the findings. The Ethics Committee at the University approved the study.

Data collection

Personal audio-taped narrative interviews were conducted with the participants (Sandelowski, 1991). The interview focused on the partners' experiences during the time their critically ill spouse was in the ICU. The interviews were conducted approximately two to nine months after the critically ill person had been in the ICU. The participants were asked to talk about daily life and family life during this period, about the information they received and their relations with the staff. Clarifying questions were used, e.g., What happened next? How did you feel then? Can you give an example? (Kvale, 1997). The interviews lasted for approximately 45–70 min and took place in a quiet room in the participants' homes ($n = 6$) or in a public building near their homes ($n = 1$), in accordance with their wishes. The interviews were later transcribed verbatim and the transcriptions were reviewed for accuracy by one of the researchers.

Data analysis

The interview texts were analysed using a qualitative thematic content analysis (Baxter, 1991; Downe-Wamboldt, 1992; Woods and Catanzaro, 1988). Each interview was read through several times so that the researchers could gain a sense of the content (Sandelowski, 1995b). The whole text was then read to identify meaning units, guided by the aim of the study. The meaning units were condensed and sorted into eight categories (Söderberg and Lundman, 2001; Söderberg et al., 2003). Those categories that were related to each other were subsumed into three themes, i.e., threads of meaning that appeared in several categories (Baxter, 1991). The two researchers independently checked and reached agreement on the categories.

Table 1 Overview of themes ($n = 3$) and categories ($n = 8$) constructed from the analysis of the interviews with partners of people in an ICU.

| Theme | Category |
|---------------------------------|---|
| Being present | Seeing the critically ill person changed Wishing to be near Showing respect |
| Putting oneself in second place | Having someone near Living a changed everyday life |
| Living in uncertainty | Being sad and afraid Knowing and not knowing Alternating between hope and despair |

Results

The themes and categories (Table 1) are presented in the text that follows and illustrated with referenced quotations from the interview text.

Being present

Seeing the critically ill person changed

Partners described it as frightening and unreal to see the critically ill person with tubes in their body during the respirator treatment. It was terrible to see the critically ill person so changed and to see all the equipment that surrounded them. "When you came in and had never seen anyone on a respirator ... a tube in their mouth, needles along their whole arm and the respirator sounds when he breathed ... I have to tell, it was a shock" (I 4).

Several of the partners expressed their horror at seeing and knowing that the critically ill person had wounds that were open or had a pelvis that was dislocated. When the wounds later healed or the pelvis was stabilised, they felt much better. "Then they came from the operation ... they didn't close his wound, because they had to see ... if they had stopped the bleeding. It was hard ... before they could put stitches in him" (I 1). Partners described that it was hard to see the critically ill person confused after awakening from the respirator treatment. "The most unpleasant thing was when they woke her up gradually, and finally she got to the stage where she could register things ... but she couldn't fix her eyes at all" (I 6).

Wishing to be near

Partners felt that the only thing that was important for them was to be with the critically ill person.

The staff also exhorted them to stay close and to speak to the critically ill person. "I stroked him on the cheek, held his hand, scratched his hair because that is what he likes most, and then I just sat looking at him" (I 4). Two of the partners felt it was hard to talk to the critically ill person during respirator treatment. They knew that the critically ill person could hear them, but they still felt strange. One partner described it as being difficult to touch the critically ill person during respirator treatment. "When he was going back to the operating theatre, they said when I phoned ... you can certainly come and say hello to him ... I don't think I went and said hello to him, I just stood there and looked at him ... it felt strange" (I 2).

Partners wanted to help, for example, they tried to prevent the critically ill persons from getting pressure sores by massaging them, and they felt good doing this. "I took part to some extent in his care. I tried to take care of his mouth or see to the air thing that used to come loose sometimes and such simple things ... that part was actually positive" (I 3). They had confidence in the staff and wanted them to handle most of the care of their critically ill spouse. Mediating information about the critically ill person to the staff was an important task for partners. They described how they brought things from home that were important for the critically ill person, for example, a particular pillow or music they knew that the spouse liked. "He also had a pillow of his own and they were not allowed to take it away because it's a special pillow ... that was an important thing" (I 7).

Showing respect

Partners said that they felt respect for the critically ill person and therefore chose to leave the room when she/he was to be nursed or undergo treatments. For partners it was important that the staff showed respect for the critically ill person and acted as if the person was conscious and could hear everything. They reacted if a member of staff spoke as if the critically ill person could not hear them. "They were good, the nurses, acting as if my husband were conscious ... but he [the physician] was the only one who didn't. He made a long speech there, just stood there smiling ... I think it was terrible talking like that" (I 3). If the critically ill person shared a room with another patient, partners described how they avoided talking because other could hear them. "You heard everything, talk, even though those equipments sound ... and then you sit quiet and can't relax" (I 5).

Putting oneself in second place

Having someone near

Partners said that the whole family was influenced by the serious situation. Apart from the critically ill person, partners described how they had to think about their children, grandchildren and/or their own parents. At the same time the family was an important support in this crisis situation for the partners and they felt alone when they were waiting for family and friends to get to the hospital. They were worried about how the other family members would cope with the situation. They appreciated grandchildren, who were young children, being allowed to be present and that they also wanted to be present. "He sat holding his grandfather's hand all the time ... Yes he is a wonderful kid; I think it was he who made him better then" (I 1). The allocation of responsibility within the family was changed, the family tie was strengthened and the family members came closer to each other. The partners felt a need to get support first and foremost from a close friend or a family member. "It has brought the family closer to each other in some way. We are a bit more honest with each other, that's something we gained ... but it's rather a high price" (I 3).

Partners described that the staff had asked them if they wanted to meet an almoner or a hospital priest, but they did not feel the need at the time. They considered it to be important to decide for themselves whom they wanted to talk to. One partner felt indignant that she had been forced to talk to the priest at the hospital. "I don't mind priests, not in any way, but I couldn't see what good it could do, but he [the nurse] was so insistent. Finally I said: Good heavens bring the priest then ... and a young girl came ... it was so pathetic ... we went on talking and she didn't know what to say" (I 3).

The partners appreciated the staff was always being there during respirator treatment. It provided a feeling of security that the critically ill person was under constant supervision. It also meant that the partner had someone to ask if they needed to. "They were a huge help, I mean having the staff we were so lucky to have ... I mean then you don't need any outsiders" (I 7). To talk to close relatives of other critically ill people and the knowledge that others were in the same situation were described as strengthening. Partners also expressed that they needed time to themselves to gain strength (e.g., to work in the greenhouse or do some carpentry work). They appreciated the relatives' room that was situated in the ICU, as they could be in the room and yet still be close to the critically ill person.

Living a changed everyday life

Partners described how daily duties became unimportant because their whole existence was focused on their critically ill spouse. All the partners stated that they did not sleep at all the first few nights when their critically ill spouse was in the ICU. The following nights they slept fitfully, but they did not feel the need to sleep. One partner said that since she could not sleep, she got hungry instead; other described how they seldom or never felt hunger. They tried to eat cooked food but they mostly ate sandwiches. "If no one told me to go and eat ... I didn't think about eating for my self, I was never hungry" (I 4).

When they went home they were always prepared for a phone call from the hospital. As one of the partners said: "I was lying there waiting for the phone to ring ... during the night, because they would call if anything happened ... I couldn't relax, I lay and waited and waited for the phone to ring" (I 4). The partners could not risk taking a sleeping tablet or a glass of wine because they were afraid of not hearing if the phone rang or that they would not be able to drive to the hospital. They wished that during critical periods it had been possible to spend the night near their critically ill partner. Alterations were also seen at home when partners did not care about things that had been important before. They felt that there was a lack of both the strength and the will to do anything at home. "It's like standing in a garage with lots of tools in your hands and you are working, and then suddenly you just let go of everything and just stand there ..." (I 6).

The partners forced themselves to do errands and they did not have the strength to look after pets as usual. Laundry came second and one partner said that he did not have the strength to put the washing up in the dishwasher. "The sink was completely full before you could manage to get up and put it in the dishwasher; we have a dishwasher you know, so it was only a matter of putting it in the dishwasher, but not even that was possible" (I 6). Daily duties were also altered for the rest of the family, the children for example, found it difficult to do their schoolwork.

Living in uncertainty

Being sad and afraid

Partners described how they felt shocked, vulnerable and full of sorrow. They were very sensitive and it was a hard time. "... you are at the lowest point about, what can I say, the strength to manage everything. You can be strong in one way, but anyhow you are grieving and confused and you are thinking forward to what?" (I 7). Partners worried

about the future for their critically ill spouse, but also for the whole family, concerning practical matters. One partner said that she was worried for the child she was expecting and that the child would never meet his or her father.

Knowing and not knowing

The hardest thing for partners was being forced to wait for information and not knowing whether their critically ill spouse would survive. They were compelled to wait for answers. No one could tell them what the outcome would be for the critically ill persons. "It's terribly hard when you don't know how it will end ... and don't know anything ... I cannot describe how you feel in words" (I 4). Partners waited for their critically ill spouse to regain consciousness so they could find out whether they had suffered brain damage or were paralysed. This waiting was prolonged and very difficult for them. Partners found it important that the information was honest and straight, even if it was negative. They thought that some of the staff did not dare to tell the truth and that they had to prize information out of some of them, "... either it's no better then they say; well, we have to take one day at a time ... if there is any recovery they will tell you. It's like you come to an agreement about a kind of language ..." (I 3).

Partners felt secure when it was possible to phone the staff at any time to get information. Most of the staff kept them informed the whole time about what was happening to the critically ill person. When partners knew about the equipment they felt more secure. "They told me about what they were doing and what sorts of medicine were involved ... I mean, what they didn't tell me I could ask about and get answers" (I 7).

Waiting a long time to get information from the physicians made the situation worse for the partners. If they received information and did not understand, they asked the nurses to explain. It was also frustrating to receive different orders, one partner felt indignant because the physician had changed the medication without informing the rest of the staff. Another felt that they had been ejected from the ICU when the staff suddenly said that the critically ill person was conscious enough and would be transferred to a nursing ward. "It was almost worse because he was conscious ... he was so confused, so frightened, angry and then it felt like somebody had thrown us out in to an empty nothingness" (I 3).

Alternating between hope and despair

Despite the fact that partners were sad and unhappy, they felt simultaneously an unbelievable

strength. They said that earlier they would never have believed that they could cope with such a situation. It was much harder than they had ever imagined, but that there was no choice. Regardless of the prognosis for their critically ill spouse, the hope existed that they would recover, "... in reality I felt really bad. You are capable of doing much more than you believe ... you cannot just lie down and die ... maybe it will go well and it did ..." (I 3).

Partners described how sometimes the information had been too discouraging. They had a feeling that some of the staff was of the opinion that they did not understand the gravity of the situation. They thought that as long as their critically ill spouse was warm and could breathe, there was hope. It was a joy when partners noticed some sign of recovery. One partner described how she looked for signs of recovery in her husband but felt that she was not even allowed to hope. "If the fever was low when you left then it was 39.9°C when I came back ... you cannot even hope without being hit hard. It's actually more like fate ... it was very difficult" (I 3).

Partners said that it felt good after the critical illness to visit the ICU and to meet the staff. It was a way to bring the time in ICU to an end. Partners thought that they had not had the time to think about themselves and they felt tired afterwards. They could be sad and cry even if everything had gone well. "I know I felt I was rather tough in a way, but I think it's afterwards, well, like I wanted to cry" (I 2).

Partners expressed an increased anxiety that something else might happen to their spouse. One partner checked whether her husband was really alive when he slept at home. They tried to look forward and one described how she had come to realize how important her husband was and how quickly life could change. "We have stronger ties to each other. You really feel how much he means to you, because otherwise you take each other for granted. You can quarrel and say stupid things, but after this experience you feel that you start to think about what you are saying, because it can happen so fast ..." (I 4).

Discussion

The aim of this study was to describe partners' experiences when their critically ill spouse received care in an ICU. This study shows that for partners it was important to be near the critically ill person who meant everything to them. The important things in life were changed and there was an

ever-present worry about how things would be in the future.

In this study partners found it was difficult to speak to and touch their critically ill spouse who was anaesthetized and connected to various machines in an unfamiliar environment. Kleiber et al. (1994) found that the feeling family members identified during the first day after ICU admission was fearfulness. Fear was a reaction to the unknown, unexpected and uncontrollable situation. Family members felt angry because they could not help the critically ill person and thought that it was not fair that this had happened to them. The partners in this study felt it was difficult to see that the critically ill person's body was injured and had open wounds. According to Corbin (2003) the familiar body can become frightening in disease. Comparing the body with how it looked previously can result in a feeling of loss and a changed identity.

It was important for partners to have the opportunity to be near to their critically ill spouse. They wanted to participate in some parts of the care, but thought that the staff should be in charge. According to Andershed and Ternstedt (2001) relatives in palliative care wanted to be close and take responsibility for seeing that the situation for the ill person was as good as possible. Noyes (1999) found that mothers to critically ill children highlighted the importance of being reunited with their child and also how important listening, talking and doing things for their child were.

In this study partners emphasised the importance of respecting the critically ill person's dignity as much as if he/she was conscious. In the Meiers and Tomlinson (2003) study, families with a child in a paediatric ICU desired to protect their child. Edlund (2002) emphasised the importance of according ill people respect and dignity, even in situations when they were asleep or unconscious. This illustrates the meaning of seeing, showing respect and confirming the other person's integrity and dignity. According to Eriksson (2001) there is no situation where a person can be considered as unworthy of participating in and shaping their own life. If the person is unwell, dignity can be maintained by acting as one would have, if it were possible.

Being there for their critically ill spouse and the family was the most important thing for partners, other things were non-essential. According to Lögstrup (1992) there is an ethical demand to take care of the other person's life in the way which is the best way for them. Lévinas (1990) emphasised the responsibility, which can be compared to a vocation, of serving the other, which can mean not leaving the other person alone. Martinsen (1993) based on Lögstrup, stated that humans do not live

an isolated life; we are interdependent on each other. This interdependence is particularly clear in connection with illness and suffering. It is a dependence which demands a humble response through caring. For [Martinsen \(1989\)](#) caring constitutes the most important fundamental requirement of human existence, where caring means consideration for the other and acting for the other's best together with the requirement to care about the other person's life in all situations in life.

Partners were concerned about the critically ill person and how the rest of the family would handle this situation. It can be compared with [Hall \(2004\)](#) where grandfathers of critically ill small grandchildren described a double concern; they were concerned both for the critically ill grandchild and for the grandchild's parents. Partners wanted to have members of the family and friends close by as support. They also needed moments when they could be alone to think in peace or to provide an outlet for their feelings. According to [Twibell \(1998\)](#) relatives needed help from family members, friends or staff as their first choice. They wanted people that they could rely on and gain support from, but at the same time they needed a quiet, private space.

The result of this study shows that when children and grandchildren could be with the critically ill person it gave the whole family confidence. [Clarke and Harrison \(2001\)](#) found that the benefits of children visiting adult family members in an ICU were an increased understanding and involvement within the family group in the crisis and reduced feelings and fears of helplessness, guilt and abandonment. Visiting provided the child with the reassurance that the family member was alive and had not left permanently. It also reduced misconceptions about the family member's illness and the hospital environment. It could help the children to deal with and integrate a stressful situation in their life. According to [Gavaghan and Carroll \(2002\)](#) it was important for the children to be prepared prior the visit of a close relative in an ICU and to talk to about it afterwards.

Partners felt that they gained support from meeting relatives of other patients in the ICU because of the similarities in their situations. According to [Kallenberg \(1992\)](#) exchanging stories about illness, pain, grief, loss or sharing suffering can create a strong intimacy and friendship between different people. [Kleiber et al. \(1994\)](#) believe that the support among relatives who met in an ICU visitor's room was based on empathy. They gained support from knowing there were others with similar problems; they understood each other.

In this study no participant chose to receive support from an almoner or priest, they preferred to talk to people they already knew. According to

[Stubblefield and Murray \(2001\)](#) parents of children who had undergone lung transplantation saw professional counselling as a valuable source of support but they were hesitant to seek it. The hesitancy may reflect their desire to be perceived as ordinary rather than different. In this study partners described the staff in the ICU as a support, which illustrates the importance of interaction between the close relatives and the staff. [Lögstrup \(1992\)](#) writes about the trust that exists towards unfamiliar people and that doubts arise first when there is a reason. When partners felt safe with the staff they also felt confident. According to [Söderström et al. \(2003\)](#) expressed nurses in ICU that the creation of an open and trustful relationship with the patient and the close relatives was one of the most essential and demanding parts of nursing care.

Partners were in despair over what had happened to their critically ill spouse and filled with dread about how life was going to be for the whole family. The waiting was especially hard. Their life had changed rapidly and no one could give them any answers to all their questions. [Morse \(2000a\)](#) stated that when a person falls critically ill it is a situation which is hard to understand. The initial reaction when something terrible happens, like when a person is falls ill, is a period of shock when everything that is happening feels unreal ([Morse, 2000b](#)).

Partners said that information made it easier to accept and understand what was happening. [Kosco and Warren \(2000\)](#) showed the importance of getting information and knowledge about what was happening to the critically ill person. [Twibell \(1998\)](#) emphasised the significance of following early contact between relatives and staff, offering the relatives appropriate and specific explanations throughout the whole hospitalisation period. Further, Twibell noted the importance of arranging time each day with family for patient updates, encouraging the family to ask questions, being honest and accurate to increase professional credibility and explaining procedures to the family.

Partners felt hope and it was essential for them to be able to feel hope and see something positive, even though the prognosis was negative. [Patel \(1996\)](#) states that hope could be to see the situation in another light. Hope exists even when people face serious threats such as the loss of life. [Twibell \(1998\)](#) noted that for the hope to be realistic the relatives had to be assisted to visualise and verbalise realistically how the situation might have a positive outcome and had to identify short-term goals for the critically ill person or family which could be met each day.

The result shows that partners can cope with more than they thought they could. They were subject to a variety of feelings, simultaneously experiencing hopefulness and strength on one hand and despair, amounting to suffering on the other. The partners reported that they also re-evaluated their lives. According to Morse (2001) suffering could be perceived as comprising two behavioural states; endurance and emotional suffering. Endurance is a strategy that enables the person to do what must be done, for example, a partner of a seriously ill person maintains control so as to be there for the other person (Morse, 2000b). A person who is suffering emotionally is filled with sadness and may cry constantly. When the suffering has been worked through, people report that they re-evaluate their lives; they live life more deeply (Morse, 2001). The suffering in itself has no meaning, but the experience of suffering can have a meaning (Eriksson, 2001; Lindholm and Eriksson, 1993).

The results of this study can be compared with those of other studies where critically ill patients who have been treated in an ICU have described their experiences. They stated that during their stay in an ICU it was important to be close to their family and friends, to be able to feel hope and security and to know what was happening (Bergbom and Askwall, 2000; Granberg et al., 1998; Hupcey, 1999, 2000). It is interesting to note the similarity in the results from these studies and in this study.

Conclusion

The whole family is influenced when a family member is in an ICU. This study shows how important it was for partners to be near to their critically ill spouse even if the environment was frightening. Partners want to know about their critically ill spouse's situation and this information must be supplied by the staff. The partner also need to be aware of the care planned for the critically ill person. We consider this to be the basis for the staff in their support of partners in an ICU.

Limitations of the study

The results from this study cannot be generalised as this is not the goal of qualitative research. Instead the result can be transferred to similar situations if the result is modified to comply with the context (Polit and Beck, 2004). The time frame for the interviews differs between the participants

and this fact could have influenced the results. The participants' memory could be biased, however, none of the participants had a problem remembering and narrating their experience of this serious event.

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Paper II

Receiving power through confirmation: the meaning of close relatives for people who have been critically ill

Åsa Engström & Siv Söderberg

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Correspondence to Å. Engström:
e-mail: asa.engstrom@ltu.se

Åsa Engström MSc RN
Lecturer and Doctoral Student
Department of Health Science,
Luleå University of Technology,
Luleå, Sweden

Siv Söderberg PhD RNT
Associate Professor
Division of Nursing, Department of Health
Science, Luleå University of Technology,
Luleå, Sweden

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Abstract

Title. Receiving power through confirmation: the meaning of close relatives for people who have been critically ill

Aim. This paper is a report of a study to elucidate the meaning of close relatives for people who have been critically ill and received care in an intensive care unit.

Background. Falling critically ill can bring about a difficult change in life. In previous reports such events are described as frightening experiences, and close relatives are described as an important source of support in this difficult situation.

Method. A purposive sample of 10 adults, eight men and two women, narrated how they experienced their close relatives during and after the time they were critically ill. The data were collected in 2004. The interview texts were transcribed and interpreted using a phenomenological hermeneutic approach influenced by the philosophy of Ricoeur.

Findings. One major theme was identified, experiencing confirmation, with six sub-themes: receiving explanations; a feeling of being understood; a feeling of safety; gaining strength and will-power; having possibilities and realizing their value. Close relatives served as tools for the person who was ill, facilitating better communication and an increased ability to do various things. Simultaneously, feelings of dependence on the close relatives were expressed. There were descriptions of loneliness and fear in the absence of close relatives and, in order to feel safe, the participants wanted their close relatives to stay near them.

Conclusion. Close relatives are vital, as they are the ill person's motivation to stay alive and to continue the struggle. Their presence is of great importance for the ill person and must be facilitated by staff.

Keywords: critical care, empirical research report, hermeneutic phenomenology, interviews, nursing, relatives, support

Introduction

The onset of an illness is accompanied by acute awareness of the unpredictability of the familiar world. In experiencing critical illness, the taken-for-granted quality of daily life is

called into question and the integrity of one's own self is threatened (Toombs 1993). People have described how becoming critically ill was felt as a complete disruption of their everyday lives, and that the support close relatives gave was essential (Parker 1999). Close relatives also describe

these changes as dramatic. It is vital for them to be with the critically ill person and to know what is happening (Burr 1998); other aspects of daily life feel unimportant for the close relatives (Engström & Söderberg 2004). In his study, we focused on the meaning of close relatives for adults who have been critically ill and cared for in an intensive care unit (ICU) as part of a qualitative inquiry into close relatives in the context of critical care nursing.

Background

To be critically ill in an ICU means confronting a life-threatening illness in a high technology environment. Not being able to breathe on your own or talk to people, because of the need for ventilator support, is described as frightening (Gjengedal 1994, Arslanian-Engoren & Scott 2003, Löf *et al.* 2006). When critically ill people are intubated they feel exhausted and experience impaired ability to communicate, which in turn leads to feelings of panic and frustration (Hafsteindóttir 1996, Carroll 2004). In such situations they describe the presence and support of close relatives as valuable (Hafsteindóttir 1996, Magnus & Turkington 2006). If no-one understood what the critically ill people tried to say, they felt like giving up (Hafsteindóttir 1996, Johnson *et al.* 2006).

Close relatives promoted reassurance and feelings of protection simply by being with the critically ill person (Bergbom & Askwall 2000, McKinley *et al.* 2002, Arslanian-Engoren & Scott 2003). The feelings of these people on waking up after sedation were often characterized by emptiness and disorientation. In this chaos, close relatives constituted a connection to reality that brought order and security (Morse & O'Brien 1995, Granberg *et al.* 1998, Magarey & McCutcheon 2005). Bergbom and Askwall (2000) found that critically ill people received the greatest help from visits by those with whom they had good relationships. It was their close relatives on whom they could rely and who cared for them. According to Hupcey and Morse (1995) and Hupcey (2001) the quality of social support is subjective and only the ill person can appreciate it. Having close family members present is preferable to having other visitors because the presence of the former requires little effort on the part of the ill person.

People cared for in ICUs feel that they have caused their close relatives suffering because of their critical situation (Bergbom & Askwall 2000); others feel that their dependency after their critical illness is a burden to their close relatives (Maddox *et al.* 2001).

To summarize, the literature shows that close relatives are an important source of support for people who are critically

ill. Furthermore, it demonstrates that there is a lack of research about the meaning of the lived experience of close relatives for people who have been critically ill and cared for in an ICU. Toombs (1993) claims that gaining an understanding of the meaning of illness is the basis for understanding the meaning of being ill: in other words, one must learn, recognize and consider the human experience of illness. Knowledge about the meaning of people's experiences is a prerequisite for improving the quality of care.

The study

Aim

The aim of this study was to elucidate the meaning of close relatives for people who have been critically ill and cared for in an ICU.

Design

As the aim was to elucidate meaning, a phenomenological hermeneutic approach influenced by the French philosopher Ricoeur (1976) was chosen for the study. Lindseth and Norberg (2004) have further developed and described the theory of interpretation presented by Ricoeur (1976) as a method applicable to researching lived experience. The phenomenological hermeneutical method used for the interpretation of interview texts consists of three interrelated phases of interpretation: naïve understanding, structural analysis, and comprehensive understanding and reflections (Lindseth & Norberg 2004).

Participants

The participants were a purposive sample of 10 adults, eight men and two women. The study was conducted in the north of Sweden and participants were recruited from ICUs in that area. The inclusion criteria were that the participants had been critically ill, mechanically ventilated for 24 hours or longer in an ICU, were adult, were interested in talking about their experiences and had at least one close relative who had visited them in the ICU and hospital ward. Five participants were recruited from the study by Engström and Söderberg (2004). These people were requested to ask their spouses, who had been critically ill, whether they would be interested in participating in our study. Two of the spouses had died, but the remaining five were interested in participating. After these interviews, we found that it was necessary to recruit more participants to achieve variation and a deeper understanding of the

phenomenon under study. Therefore, another five participants were recruited; a critical care nurse working in an ICU selected and mediated contact with five people who fulfilled the inclusion criteria, and they were all interested in participating. Letters with more information about the study were then sent to the total of 10 people who had been invited. The letters contained an inquiry as to whether they wanted to be contacted to decide a time and place for the interviews; all answered the letters and agreed to participate.

The participants were aged between 22 and 73 years (median = 58), and had been on a ventilator for 1–23 days (median = 14). They had all been acutely, critically ill and had a medical diagnosis of sepsis, multi trauma or aortic aneurysm. After discharge from hospital two of the participants returned twice to the ICU because of breathing problems. At the time of the interviews they had all returned home. As we wanted to study the meaning of close relatives during and after the participants' critical illness there was a time lapse for all of approximately 1.5 years from when the participants became critically ill to the interviews. Every participant had at least one person they described as a close relative, as the one person who was especially important and close to them. One participant said that this person was his mother, for the others it was their partner. Participants also described their children, parents and siblings as close relatives and it was their company the participants preferred during and after the time they were critically ill.

Data collection

Personal interviews, using a narrative approach, were conducted (Sandelowski 1991). At the start of interviews, participants were asked to describe their experiences of close relatives during and after the time they were critically ill. Broad clarifying questions were asked such as: What do you mean? (Lindseth & Norberg 2004). The interviews took place in participants' homes ($n = 8$) or in a public building near their homes ($n = 2$); their close relatives were not present during the interviews. Participants were informed about the general nature of the study by letter and before the interviews started. The interviews were carried out by the first author in 2004, and lasted from 30 to 90 minutes each. They were tape-recorded and later transcribed verbatim.

Data analysis

In the first phase of the interpretation process, the naïve understanding, we read through the text several times, as open-mindedly as possible, allowing the text to speak to us,

to grasp its meaning as a whole. In the next phase, the structural analysis, we divided the text into meaning units, i.e. a sentence or several sentences that had a similar meaning in relation to the study aim. Each meaning unit was then transformed through condensing and abstraction to produce a formulated meaning. The formulated meanings were then related to each other, reflected on and organized into one major theme and six sub-themes. The major theme and sub-themes were compared with the naïve understanding for validation. In the third and final phase of the interpretation we read the text again and formulated a comprehensive understanding and reflection. This was constructed based on the naïve understanding, the structural analysis, our pre-understanding and the literature (Ricoeur 1976, Lindseth & Norberg 2004).

Rigour

The interpretation presented here is the one we found to be the most credible understanding of the text. According to Ricoeur (1976 p. 79), 'an interpretation must not only be probable, but more probable than another interpretation'. We were aware of our preunderstanding as nurses and as nurse researchers, and tried to be as open as possible to the text by continually and critically reflecting on the interpretation. According to Lindseth and Norberg (2004), one understands in relation to one's preunderstanding while interpreting a text. While we were interpreting the interview text we broadened our preunderstanding by studying relevant literature. The chosen literature illuminated the interview text and in turn the interview text illuminated the chosen literature (Lindseth & Norberg 2004). Both authors participated in the interpretation process, and also discussed it with research colleagues. The structural analysis is the objective section of the interpretations of the text, to which further interpretations can be referred; it serves as a form of validation (Ricoeur 1976, Lindseth & Norberg 2004). The findings are illustrated with quotations from the interview transcripts. According to Holloway and Wheeler (2002), confirmability exists when readers can trace data to their original sources.

Ethical considerations

A university ethics committee and the heads of three ICUs in the north of Sweden approved the study. People interested in participating were assured that participation was entirely voluntary and that they could withdraw from the study at any time. They gave informed consent to participation and were guaranteed confidentiality and anonymity.

Findings

Study limitations

Our findings cannot be generalized, but can be transferred to similar situations or participants. We have presented the context, procedure and analysis as accurately as possible to help the reader to determine the level of trustworthiness and transferability of the study (Holloway & Wheeler 2002). Participants were recruited from two groups, but the criteria for participation were similar. We contacted participants with the help of partners of critically ill people from our previous study; one risk was that, if the relationship between them was no longer good, they might not pass on our invitation; however, this did not happen and all invitations were passed on. The amount of data gathered was extensive, with many hours of participant interviews containing rich descriptions and variations, making it possible to achieve a deeper understanding of the phenomenon under study. According to Fossey *et al.* (2002), data of sufficient depth need to be gathered to enable full descriptions of the phenomenon being studied. Our participants did not remember all the events or exactly when and if things had happened during the time they were critically ill, but they could all talk about their close relatives and experiences connected with what these meant to them during and after the time they were critically ill. According to Russell (1999), Maddox *et al.* (2001) and Crocker (2003), people's recollections of events in the ICU when they were critically ill can be minimal, patchy or delusional. Morse (2000) states that it is immoral not to contact them, because they are in need of understanding. Asking people to tell their stories, on their own terms, allows them to enter the experience at their own pace. This can result in a resurgence of the memories and emotions and a recalling of experiences, which our participants also noted. Our participants seemed to have what could be described as 'good relationships' with their close relatives and that is probably what is distinctive about the relationship with a close relative. We do not know from this study what or who could replace close and supportive relatives in the struggle to survive critical illness in those lacking such people. This can be seen as a limitation or as a suggestion for further research.

Naïve understanding

The initial interpretation was that close relatives gave participants a reason to continue their struggle. Their presence was felt during participants' critical illness, and gave them a power which only close relationships could give. Close relatives were the participants' interpreters in

communication with others, as being critically ill with an endotracheal tube in one's throat made it difficult to communicate. Close relatives also could mostly understand what patients meant or felt. To feel safe, participants wanted their close relatives to stay near them, as feelings of loneliness and fear were described as being engendered by their absence. It seems that close relatives were participants' tools, enabling them to do various things, but at the same time participants expressed dependence and guilt. Relationships between participants and close relatives seemed to grow stronger, and they expressed the feeling of caring more for each other after the experiences they had shared.

Structural analysis

The structural analysis resulted in one theme and six sub-themes. These are presented below and are illustrated by quotations from interview texts.

Experiencing confirmation

The theme 'experiencing confirmation' was constructed by the sub-themes: receiving explanations; a feeling of being understood; a feeling of safety; getting strength and will-power; having possibilities and realizing their value.

Receiving explanations Participants said that it was vital for close relatives to be near in the ICU so that they could see someone they recognized. With the help of close relatives, they could obtain explanations about where they were and what had happened. It was also a way for participants to get information about the world outside the hospital. While participants were critically ill they experienced delusional memories, such as nightmares, in which both participants and close relatives were often involved. They were unsure whether their memories were real and they described how close relatives were able to help them remember what had really happened:

I dreamed about many different things, like I was hurt in other ways too...then I tried to ask, but I had this kind of tube in my mouth. My dad was there and he could interpret what I was trying to say, so then he explained why I was there.

A feeling of being understood Participants found it hard to communicate while critically ill, and it was frustrating when no words came out when they were intubated. They described feelings that their close relatives really tried to understand them, for example by reading their lips. They also described how close relatives usually understood what they meant and saw, for instance, when they were in pain or felt

tired. They felt that they could communicate with close relatives almost without words, and described how close relatives told the staff what they had been trying to say. In situations when close relatives could not understand what they tried to say, participants said they felt terrible:

I had stomach pains and I tried to tell them (the staff) – I moved my mouth but no sounds came out. It was very hard not being able to talk, and then it was good she (his mother) was there because she sort of saw what I was trying to say.

It was easier to talk, even though I couldn't talk, to her compared to the others. It was easier to ask her if I wondered about something or tell her when I felt scared. It was easier to talk to someone I knew, instead of someone I didn't know...the most important thing was that she was near.

Feeling of safety Participants described being aware that close relatives were present while they were critically ill; they had recognized their voices, felt their touch and recognized their smell. They said that the presence of close relatives gave them a feeling of security, and when they were absent participants felt lonely and trapped in their beds. Feelings of happiness were described when close relatives arrived, and when they left the participants counted the hours until their next visit. They wished to have close relatives nearby as much as possible in the ICU to feel safe, and described wanting only close relatives to visit them during their time in ICU, when they felt vulnerable, worn out, ill and unable to speak:

I felt safe having someone you could tell what you were thinking about, or ask for help... When my husband was there we talked and he read for me. But you don't have the strength to do that all the time, so then I rested and he read his own books...

Having them near was good... Afterwards I've realized this meant a lot to me...their presence made me feel safe.

Gaining strength and will-power Participants described close relatives as their reason for continuing to struggle. They felt that they were losing control and could die when close relatives were absent from the ICU. It was the thought and presence of close relatives that gave them back their will to live when they felt like give up. They felt that, because their close relatives cared, they did not want to fail them by giving up as they were the most important people who existed for them:

Thoughts of my family made me struggle on. I don't know, but my children were the ones who drove me on. I had to fight on. I saw how

they and my husband cared for me and had to manage everything. Then I felt I can't fail them; I have to continue to struggle.

It was like they gave me power in some way, because sometimes I felt like: God, if I could fall asleep forever. I felt that many times, the mornings especially were terribly hard...if I hadn't had my close relatives, I don't know how I would have managed it.

Having possibilities Participants described the involvement and support of close relatives as being of great value. They preferred, if possible, to get help from them rather than from staff and described how close relatives helped the staff by encouraging patients to do training exercises, and this led to faster rehabilitation. Participants also described how close relatives made it possible for them to go and then, eventually, be at home. They did not know how they would have managed to get through the critical illness and then to cope afterwards without them:

I don't know if I would have handled it without them (his parents). They have helped me with everything. I wouldn't have been able to eat from a plate without them. I have had them at home continually and it's been a great help in many ways.

Participants described days when they were in pain, felt depressed and wanted to, but could not, do various things. It was on such days that they felt they were not easy for their close relatives, who had to give up a lot of things to be with and support them. Close relatives had to take on a greater part of the work in the home when participants could not do the things they had been able to do before. Participants felt they had caused these relatives suffering when they became critically ill. They thought a great deal about how hard the situation had been for the close relatives, who had been forced to live with the uncertainty of participants' survival:

I think the one who has suffered most is my wife, because when I was ill I got help, but it is much worse for the person who sits beside you and is worried...

Realizing their value Participants described having a feeling of increased anxiety that something terrible would happen to their close relatives and that they would not be able to handle the situation if their close relatives were, for example, in a car accident. They said that their relationships with close relatives had been influenced. Although it had been a difficult time, they described how after sharing the experiences of their critical illness, they had come closer to these relatives. A deeper friendship had grown and participants had become more aware of what and who was important in their lives.

They mentioned that they and their close relatives spent more time together, they became more aware of where they stood with each other, and they cared more for each other:

It has brought us together. We see a great deal of each other within the family; we did that before too, but now I think it's with more consideration.

Comprehensive understanding and reflections

When participants were ill in the ICU, they appreciated seeing close relatives who helped them to understand what had happened. According to Ricoeur (1976), to be able to understand we need explanations, and with the help of explanations we can understand, as understanding and explanation overlap and intertwine. Receiving explanations meant that participants' experiences of illness were validated and, according to Toombs (1993), explanations can allow a person to make sense of the illness experience.

Participants described how close relatives really tried to understand them. To be heard, listened to, acknowledged and responded to directly means that one's experience is facilitated and encouraged, which confirms one's worth (Cissna & Sieburg 1981). Having others listen and empathize are forms of communication that imply confirmation (Nåden & Eriksson 2000). Close relatives could interpret the feelings that participants experienced while they were critically ill. According to Sundin and Jansson (2003), understanding and the state of being understood between two people is communion. This communion and communication would have been impossible for participants if their close relatives had been absorbed by their own situations or had concentrated on their own feelings and anxieties, because then it would have been impossible to receive and incorporate the message of the other (Marcel 2002a).

Participants did not remember all the events during their critical illness and they told close relatives about their experiences. To be allowed to feel what you feel and be respected for it is to be trusted and confirmed. It is a validation of one's experience and existence. Not being confirmed means not being seen or taken seriously, which undermines a person's dignity (Nåden & Eriksson 2000). When close relatives were not present in the ICU, participants described how they longed for them and felt trapped in their beds. According to Toombs (1993), illness is a state of disharmony which incorporates a loss of the familiar world. In this altered state, the ill person is unable to carry on normal activities and to participate in their everyday world. The natural desire to meet, communicate and unite with others is motivated by the sense of overcoming feelings of

aloneness (Mijuskovic 1979, Rokarch 2004). According to Frank (1991), becoming critically ill means losing the coherence in life; while other people can plan for the future, continue to work and so on, becoming critically ill means living a displaced life. Expression is needed to restore coherence. This implies the presence of others to share in one's humanity.

While participants were critically ill they felt safe in the presence of close relatives, who were able to provide consolation. Receiving consolation gave participants the sense that space and time were available and they were not alone (Norberg *et al.* 2001). According to Marcel (2002b), a close relative who is really present for the person with the life-threatening illness is the one who is with the ill person, with the whole of self when the ill person is in need. It is someone who the ill person feels is present and this presence involves reciprocity. Caring, being together, fellowship at work, and other kinds of social collaboration do not necessarily mean that people become closer to each other; it is the genuineness of the relationship that is important (Buber 1990).

To stay alive in order to be with close relatives became a reason for participants to continue the struggle and to try to make sense of the meaning of their existence. According to Frankl (1963), the most important strides come when one feels there is meaning in one's life. People who know why they exist are able to bear almost anything. The meaning of one's existence is something one has to discover for oneself, and it is this meaning which makes it possible to endure difficult situations. Realizing the value of close relatives and knowing that these relatives were still expecting something from them seemed to give participants a reason to live. To be loved is to have something expected of one, as expecting is a way of giving. Not to expect anything from a person is to deprive them in some way (Marcel 1978). Participants felt that they were important in their close relatives' lives and that close relatives were important in theirs. To be present in other's lives and to be confirmed by others is a desire and need that every person has (Buber 1957). The messages from close relatives to participants, which we interpreted as confirmation, were: 'You exist, we are relating, to me you are significant; your way of experiencing your world is valid' (Cissna & Sieburg 1981). Participants were strengthened when they saw how their close relatives cared for them. Confirming interactions exist when a person receives evidence that either strengthens their positive self-assessment or weakens their negative self-assessment (Gustafsson & Pörn 1994). The feeling that their close relatives turned to them was a creative act and the feeling of their acceptance involved

What is already known about this topic

- To become critically ill and dependent on other people and technical equipment means a sudden and difficult change in life.
- People who have been critically ill have described their close relatives as providing important support during and after the time they were critically ill.

What this paper adds

- Critically ill people experienced close relatives as the motivation to stay alive.
- Through confirmation given by close relatives, critically ill people received the power to continue the struggle to live.
- The importance of the presence of close relatives and of including them in the care provided.

recognition of one's self. According to Nåden and Eriksson (2000), this constitutes the foundation of confirmation.

Close relatives helped to improve participants' quality of life, but it was demanding to be dependent on them to manage various aspects of daily life. According to Eriksson (1994), people have a sense of dignity when they can carry out tasks as human beings. However, if they lose that responsibility they lose their dignity. Participants felt anxious about their close relatives' suffering and the extra work that was a consequence of the critical illness. According to Buber (1997), true sympathy is experiencing another person's special pain in such a way that one feels the specific pain.

Participants felt that their relationships with close relatives had grown stronger as a consequence of what they had gone through together. Frank (1991) described his good fortune in having his wife there to share his experiences of critical illness, and states that sharing losses and difficult experiences seemed to be the easiest way of living with them. According to Gallagher (1962), we are so constituted by our relations with others that the we creates the I. A bond of feeling can be created between people who have shared a special experience, e.g. critical illness. 'A unity is established in which the other person and myself become we, and this means that he ceases to be him and becomes thou' (Marcel 2002a, p. 33). This means being in personal communion (Marcel 2002a). It seems that experiencing critical illness, although extremely difficult to bear, can confirm and strengthen relationships between an ill person and their close relatives (Parker 1999).

Conclusion and clinical implications

When critically ill, a person often needs advanced drugs and highly technical treatment if they are to have a chance of surviving. This study shows, however, that the critically ill person needs more than medical treatment and nursing care, and the presence of close relatives should be facilitated by the staff. However, relatives can find it difficult to touch and talk to the critically ill person (Engström & Söderberg 2004). It is therefore important that critical care nurses encourage and support them to dare to talk, touch and stand close to the patient, as this is of great importance for the latter. If close relatives gain knowledge and understanding about what is happening with the critically ill person, their difficult situation will probably be eased; they can then provide support by filling in memory gaps and explaining things to the ill person. Follow-up visits to ICU can give opportunities to support the ill person and their close relatives (Griffiths & Jones 2002) by allowing them to talk about the experience of critical illness and all the feelings it raised. This can also be beneficial for critical care nurses by helping them to gain better understanding of how nursing care is experienced and how the experience of critical illness influences people's lives.

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Author contributions

ÅE and SS were responsible for the study conception and design and the drafting of the manuscript. ÅE performed the data collection and ÅE and SS performed the data analysis. SS provided supervision.

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Paper III

Close relatives in intensive care from the perspective of critical care nurses

Åsa Engström MSc, RN

Doctoral Student, Division of Nursing, Department of Health Science, Luleå University of Technology, Luleå, Sweden

Siv Söderberg PhD, RNT

Associate Professor, Division of Nursing, Department of Health Science, Luleå University of Technology, Luleå, Sweden

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Correspondence:

Åsa Engström

Hedenbrovägen Boden

SE-961 36

Sweden

Telephone: 46 921 758 75

E-mail: asa.engstrom@tu.se

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Close relatives in intensive care from the perspective of critical care nurses

Aim. The aim was to describe critical care nurses' experiences of close relatives within intensive care.

Background. There is a lack of research describing critical care nurses' experiences of the significance of close relatives in intensive care. Knowledge in this area will support critical care nurses to develop good nursing care for the critically ill person and their close relatives.

Design and method. The design of the study was qualitative. Data collection was carried out through focus group discussions with 24 critical care nurses in four focus groups during spring 2004. The data were subjected to qualitative thematic content analysis.

Results. The focus groups discussions showed that the presence of close relatives was taken for granted by critical care nurses and it was frustrating if the critically ill person did not have any. Information from close relatives made it possible for critical care nurses to create individual care for the critically ill person. They supported close relatives by giving them information, being near and trying to establish good relations with them. Close relatives were important. Critical care nurses lacked forums for reflection and discussion about the care given.

Relevance to clinical practice. This study indicates that close relatives are a prerequisite for critical care nurses to give good nursing care to meet the needs of the critically ill person. A communication based on mutual understanding is necessary if critical care nurses are to be able to support close relatives. Dealing constantly with situations that were ethically difficult without any chance to reflect was an obstacle for critical care nurses to improve their work with close relatives.

Key words: critical care nursing, close relatives, focus group discussion, nurse, qualitative thematic content analysis

Introduction

This study is part of a qualitative inquiry about close relatives in the context of critical care nursing. Critical care nursing can be defined in terms of critically ill people together with their close relatives, nurses and the environment. It constitutes the nursing of critically ill people who are undergoing life-threatening crises where they are often dependent on machines, complex drug therapies, nursing, medical and technical resources (Beeby 2000), but also on their close relatives for support (Bergbom & Askwall 2000, McKinley *et al.* 2002). Wilkin and Slevin (2004) described the nature of caring work in an intensive care unit (ICU) as professional knowledge together with feelings, competence, skills and nursing action, which involved holistic care of the critically ill person with close relatives. A previous study (Engström & Söderberg 2004) examined the experiences of partners of critically ill people in an ICU. It was essential for the partners to be near the critically ill person, they wanted information of the planned care and the situation of their critically ill spouse.

Studies (Bucknall 2003, Söderström *et al.* 2003) found that critical care nurses (CCNs) considered close relatives as a resource both for the critically ill and for themselves. The CCNs could gain an improved understanding of patients as individuals when they got to know the close relatives and critically ill people better (Hammond 1995, Ciccarello 2003). Bucknall (2003) and Coyle (2000) have shown that the continual physical presence of CCNs at the bedside of a critically ill person placed them in a central position close to both the ill person and the relatives. Gavaghan and Carroll (2002) noted that CCNs felt they were improving the outcome for critically ill people in ICU by meeting the needs of close relatives.

Cronqvist *et al.* (2001) found that CCNs felt they were forced to make difficult prioritizations in providing care because of lack of resources and heavy workload, which led to the neglect of support for relatives. Söderström *et al.* (2003) showed that creating a relationship of trust with the critically ill person and the close relatives was one of the most essential and demanding parts of nursing care in ICUs. Other studies (Scullion 1994, Ciccarello 2003, Peel 2003) have found that CCNs experienced difficulties in knowing how to communicate with relatives about impending death and supporting them emotionally. In summary, there are few studies describing CCNs' experiences of the significance of close relatives in ICUs. Increased knowledge in this area will support CCNs to develop good nursing care for the critically ill person and their close relatives.

The study

Aim

The aim of this study was to describe CCNs' experiences of close relatives within intensive care.

Design

The study has a qualitative design and a thematic content analysis was chosen for the study as the aim was to describe CCNs' experiences of close relatives in ICUs. Focus group discussions were used for data collection as this approach encourages multiple perceptions of similar experiences around specific topics; diverse options as well as shared thoughts and feelings (i.e. CCNs' experiences of close relatives). The hallmark of focus groups is the explicit use of group interaction to produce data that would be less accessible without the interaction found in a group (Morgan 1997, Barbour & Kitzinger 1999).

Participants

A purposive sample of 24 CCNs, all women, participated in the study. The criteria for participation were that the participants were registered nurses with specialist training in intensive care nursing and had worked for at least two years in ICUs. The participants were aged between 31 and 60 years ($md = 45$) and had worked as CCNs for between four and 34 years ($md = 15$). They were given information about the study by one of the researchers and the head nurse. Letters, sent to 25 nurses, gave more information to the CCNs interested in participating and 24 agreed to participate. There were four focus groups with five to seven CCNs in each group, three groups worked at the same hospital and the fourth in another hospital. After four focus group discussions the data proved to be sufficiently rich to allow deep analysis (Sandelowski 1995a). According to Morgan (1997) the goal is to have as many groups as are required to provide trustworthy answers to the research question. To achieve credibility we met the CCNs who participated in the study a second time to discuss the findings (Holloway & Wheeler 2002). We were in an agreement about the findings as the CCNs recognised them as their own experiences.

Data collection

The focus group discussions took place in quiet rooms in the hospitals where it was possible for the participants to

be seated comfortably and to see each other (Roberts 1997). The first author initially prompted the discussion with open-ended questions (Table 1), encouraged the participants to talk to one another by commenting on each other's experiences and asked further questions for clarification. The second author took notes and provided summaries to conclude the discussions (Morgan 1997, Barbour & Kitzinger 1999). The focus group discussions took place during spring 2004; lasted for 90 minutes in each group, were audio taped and later transcribed verbatim.

Ethical considerations

The heads for three ICUs in the northern part of Sweden gave their permission for the study to be performed. The participants were informed about the general nature of the study. They were reassured that their participation was voluntary and was guaranteed confidentiality and anonymous presentation of the findings. The ethics committee at the university approved the study.

Data analysis

The data were subjected to a thematic content analysis (Woods & Catanzaro 1988, Baxter 1991). Each focus group discussion was read through several times to gain a sense of the content (Sandelowski 1995b). The whole text was then read again to identify meaning units, bearing in mind the aim of the study. The meaning units were condensed and sorted into eight categories related to content. Those categories that were related to each other were subsumed into three themes, i.e. threads of meaning that appeared in several categories (Baxter 1991).

Results

The themes and categories are presented in Table 2.

Table 1 Question domains used in the study with the aim of describing CCNs' experiences of close relatives in ICUs

| |
|---|
| Narrate how you know who are close relatives of a critically ill person |
| Narrate examples of good or less good meetings with close relatives |
| Narrate situations which have been ethically hard to handle |
| Narrate about how you support close relatives |
| Narrate about changes you want to do in your work with close relatives |

Table 2 Overview of themes ($n = 3$) and categories ($n = 8$) constructed from the analysis of the focus group discussion

| Theme | Category |
|-------------------------------------|--|
| A link to the critically ill person | The voice of the critically ill person Uncertainty about who is the close relative An important and demanding part of the work |
| Getting near | Relieving the situation Keeping hope alive and being honest Being called into question |
| Wanting to do a better job | Feelings of inadequacy Absence of feedback |

A link to the critically ill person

The voice of the critically ill person

CCNs described that close relatives were important both for the critically ill and for the staff; they were taken for granted. The CCNs expected the critically ill person to have a significant other and it was frustrating if there was no close relative or if it was problem to contact close relatives:

This boy, who was here frequently with diabetes, he came alone, lying here in the ICU and they hardly phoned and asked how he was. (CCN 21)

Then we all felt bad, it was terrible. (CCN 22)

CCNs described how close relatives gave a comprehensive picture of the critically ill person, such as their daily life, interests and habits. This helped them to create individual care for the critically ill person:

Some close relatives bring pictures of the ill person in their ordinary environment. I think it's really nice, because we can't even see what they look like, with all tubes and all overweight they get. (CCN 6)

It gives you another feeling for the person you are nursing. (CCN 4)

Uncertainty about who is the close relative

When a critically ill person arrived CCNs thought about whom the close relatives were and if they knew that the person was in the ICU. If CCNs could communicate the ill person, they together decided who the close relatives were and what information the CCNs could give to them. This was difficult when the critically ill person was unconscious. When people phoned and asked questions or wanted to visit the critically ill person CCNs could not be sure whether or not they really were close relatives. If there were many close relatives CCNs asked one close relative to pass on information to the others:

When you experience there are many children involved and all of them want the same information, firsthand information, you may think one of them should be coordinator and communicate the others. (CCN 3)

An important and demanding part of the work

CCNs described how close relatives were a vital part of their work, a part that could take a lot of time and energy. Meeting parents of critically ill children or talking about organ donation with close relatives was especially demanding. If there were problems or conflicts within the critically ill person's family, CCNs felt they inevitably became involved without chance to resist. It was difficult when close relatives did not seem to understand how serious the situation was for the critically person and when they wanted CCNs to make decisions for them:

You try to tell them it's very serious ... then they ask again: Do I've to come? They want you to make the decision for them, like: No, you don't need to come, and then anything can happen as soon as you hang up. (CCN 20)

CCNs described how close relatives had become a more significant part of their work during the last few years, while others thought they had always been important. Some CCNs described how when they had just become CCNs it was hard to see and take care of close relatives. They had to concentrate on the critically ill person and the apparatus to manage their job:

This thing with close relatives has become larger and larger during the years I've worked. I don't remember any close relatives from my first five or six years, but they must have been there. They have become a huge part of our work. (CCN 6)

Getting near

Relieving the situation

CCNs said that when close relatives arrived at the ICU for the first time they tried to prepare them for the situation. They described that as the most important way to support close relatives was to be near and show that they cared. It was vital to make close relatives feel that they were important. They informed close relatives about practical things, for example, where to eat. CCNs gave close relatives chairs and encouraged them to sit near, speak to and touch the critically ill person and emphasized that the close relatives were not in the way. Sometimes CCNs felt they were not allowed to get near the close relatives although they could see their despair. Talking about daily life or laughing with close relatives felt good:

I think it's important for close relatives to forget for a while how serious things are, to let go of their thoughts if it's possible, but that's something that happens naturally, it's not something you can plan. (CCN 13)

CCNs asked close relatives to leave the room in situations where when the integrity of the critically ill persons was threatened, e.g. when attending to the personal hygiene of the critically ill person, especially if the close relatives did not usually participate in such tasks. At the same time it was natural for close relatives to take on other parts of their nursing. It could be a good thing for close relatives to have tasks that gave them a natural way to be nearer the critically ill person. The CCNs described they could be better at asking close relatives if they wanted to participate in some parts of the nursing of critically ill people, as they often forgot to ask. During emergency situations CCNs felt they could radiate coldness, because they were so concentrated. They did not think there was any problem in having close relatives present during resuscitation, but it could be hard to see close relatives grieving:

It's so enormously hard to keep on working while the patient is dying in front of their eyes. If the patient is unconscious it influences me less emotionally than having close relatives sitting there with those streaming eyes, maybe hysterical. From that point of views I should send them all out, to spare my own pain, because it also hurts getting near close relatives. (CCN 2)

Keeping hope alive and being honest

CCNs highlighted the importance of telling the truth about how serious the situation was, but at the same time they wanted close relatives to have some hope. Close relatives could hope that a miracle would happen; in such situations CCNs said that they had to let them keep their hope, but not confirm it or be unfruitful when it was unrealistic. If CCNs did not inform close relatives they sometimes felt it was like lying. When there was no hope of recovery left the only thing they could do was to be there with the close relatives and give comfort:

One hope can be for a good death, if we support them and all the close relatives can get here in time it can be a fine end. It's a kind of hope knowing the ill person will not suffer any more. (CCN 2)

CCNs described situations where it was difficult to be truthful to close relatives, for example, when physicians changed the treatment for critically ill people; one day the treatment was withdrawn and the next day it was resumed, without any explanation. CCNs felt they were not being honest with close relatives when they thought the critically ill

person would not survive but the physicians wanted to continue treatment or when the physicians did not give the close relatives enough information:

Sometimes the doctor comes and resumes the treatment, you don't really know what to do, you only do what you've been told and then you feel really bad, it's hard to explain to close relatives when they ask about what is happening. (CCN 3)

CCNs sometimes experienced that another close relative was not to be informed or called, because the close relative was not well or because there were conflicts between them. The CCNs felt it could be unfair to the close relative who was not allowed to have any information:

Ethically it was so difficult because the children absolutely didn't want the new woman to know anything, it was very clear... on the phone they said: You're not allowed to tell her anything and they were abusive. It's very hard when she's standing in the corridor at the same time as they are in the phone. (CCN 19)

Being called into question

CCNs described that close relatives sometimes blamed the staff for not giving enough information. Close relatives could be critical, stressed and aggressive towards the CCNs. If the relationship started badly it could take a while to work things out. It was difficult to know what to say when close relatives stared in an unkindly way:

... there was one occasion when one of the sons was so incredibly angry, he screamed here in the corridor and thought everything had been done the wrong way, nothing was right... you almost avoided going in there, because he was so angry you thought he was going to hurt you... it was really hard, and it wasn't me he was angry at, just that everything around had gone wrong. (CCN 16)

CCNs experienced that, sometimes, close relatives never gave the critically ill person a chance to rest and made the situation stressful both for the critically ill person and the staff:

...she was really loud-voiced and closes to him, wanted to mop his forehead while we tried to do things we felt were most important. Actually you felt as if you wanted to lift her away.... you couldn't do what you wanted to do fast, because she was in your way the whole time. (CCN 20)

Different cultures could be a problem according to the CCNs because there could be dissimilar views about things, e.g. how many visitors there could be at the same time or how feelings should be expressed:

We have such different cultures and such a thing can be problematic for us when we have grown up in a different culture. Like the thing about sound level, we are used to being quieter and almost apologise

if someone screams while they give full expressions to their feelings in an entirely different way. (CCN 22)

Close relatives could test CCNs and compare the answers they got from other personnel, or if the critically ill person was transferred from another hospital close relatives compared the care between the hospitals. CCNs discussed how different close relatives could be; some questioned everything, others were sure that everything possible was being done for the critically ill person:

Close relatives are in a dreadfully stressful situation when something acute has happened and then you can feel they are a bit aggressive towards us in the beginning because they are stressed and scared, then you have to take it easy and try to establish good relations... (CCN 8)

Wanting to do a better job

Feelings of inadequacy

CCNs described they had to take care of the critically ill person but at the same time they wanted to support close relatives. They thought it would be better if one CCN could be with close relatives and another with the critically ill person, especially when they had just arrived and during resuscitation. Some CCNs thought there was enough staff but that their deployment could be better, while others said there was no time or resources to meet the needs of close relatives. CCNs wanted to have an almoner, hospital priest or a person who could take care of deeper discussions with close relatives in ICU.

Close relatives often had confidence in the physicians, but CCNs felt they had to force some physicians to talk to close relatives. They might have to wait for a long time to get information from physicians and sometimes CCNs were left to take care of close relatives. When close relatives spoke to physicians CCNs also wanted to participate to know what had been said:

It's really important to give the same information, so you don't say anything other than what the physicians have said, but it's like you say: you seldom or never manage it; you cannot just leave the patient and go with them. (CCN 15)

CCNs wanted a larger room for close relatives as they considered the present room too small and they felt ashamed when they had to show close relatives into the cramped room. They wished they could offer close relatives the chance to sleep over. Some CCNs explained how they used to prepare close relatives for the fact that they would not be able to sleep in the ICU. Others described how they sometimes offered a bed to close relatives but at the same time felt there might be

problems maintaining the integrity of other critically ill people. CCNs lacked rooms where they could talk to close relatives in peace. They believed the ICUs were not built to accommodate the needs of close relatives in a good way.

Absence of feedback

CCNs had no supervision and felt that they needed some kind of meeting to discuss their experiences of close relatives. They also wanted to discuss goals of the care, how to meet close relatives and how to work with ethical questions:

It's so shocking and terrible for all the close relatives who arrive here, nothing worse can happen to anyone, and we are in this situation continually. I think what you were saying about a forum for us is important, because many times you arrive home thinking: Could I've done anything more or: What shall we do? When they [close relatives] are in such a state of shock that you cannot use words to explain. (CCN 14)

CCNs missed any follow-up of those who had been critically ill and/or their close relatives. That kind of feedback should, according to the CCNs, improve their nursing care by knowing how the time in the ICU was experienced and how they managed afterwards.

Discussion

This study shows that CCNs regarded close relatives as an important link to the critically person as they learnt to know and understand the person through them. According to Martinsen (1989), to understand each other there has to be something that binds us together, such as daily life. Close relatives gave CCNs information about the critically ill person's daily life, a knowledge that gave the CCNs the chance to provide individual care. This study also shows that it can be challenging for CCNs to meet close relatives. Holden *et al.* (2002) have shown that development of relationships between CCNs and close relatives demands time and energy, but it can also help to reduce stress for all concerned. It is, therefore, important that CCNs understand how their interactions can influence establishing successful relationships with close relatives.

CCNs said that close relatives had become more important over the years. This indicates that it is necessary to be aware that inexperienced and experienced CCNs may have different requirements if they are to give good nursing care concerning the needs of close relatives. As Walters (1995) emphasised, CCNs have to combine modern technology with the lived experience of critically ill people and close relatives.

CCNs supported close relatives by, for instance, giving them information. Studies (Twibell 1998, Brown *et al.* 2000,

Bond *et al.* 2003) have shown that one of the worst things for close relatives is when they get insufficient information about the critically ill person's situation or have to wait for a long time to find out what is happening. According to Holden *et al.* (2002) the communication of information is essential if any needs are to be met. The challenge seems to be to achieve a shared understanding about how the close relatives experience their situation to be able to give them the information they need. According to Sundin and Jansson (2003) communicative action is an interaction between subjects to achieve understanding. Through understanding and being understood you share the same feelings and experiences, it is a mutual understanding, which includes more than speech acts. According to Mitchell *et al.* (2003), uncertainty regarding the illness outcome may be common among close relatives of the critically ill due to the precarious nature of the illness process. The experience of uncertainty restricts one's ability to decipher and interpret a situation. Having faith and trust in the providers of the information is crucial in reducing feelings of uncertainty.

CCNs wanted to protect the integrity and dignity of the critically ill person and, therefore, sometimes asked close relatives to leave the room when giving care. According to Söderberg *et al.* (1999), meeting people with illness with respect for human dignity is the foundation for all care. When people with illness experience a threat to their integrity and human dignity it can be seen as being caused by the illness, but more particularly by the treatment they receive from other people. Concerning the participation of close relatives in ICU care Hammond (1995) think that it may not suit everyone and each situation needs to be assessed individually. According to Eldredge (2004) spouses wanted to help their critically ill partners and the types of helping were uncomplicated. The spouses described this in positive terms; they could be close to their critically ill partner and be helpful at the same time.

This study shows that CCNs usually let close relatives be with the critically ill person during acute situations. Studies (Ardley 2003, Wagner 2004) concerning inviting close relatives to be present during resuscitation show that close relatives who want to be present can then be near the critically ill person and it gives a sense of what is happening. CCNs wanted to give close relatives some hope but at the same time be honest. The desire to understand what will be of most help to the other person has to be linked to the wish to let the other be his own master and not to take over his responsibility (Lögstrup 1992). According to Burr (2001), hope for close relatives was that the critically ill person would survive. If that was no longer possible, they hoped for a peaceful death. Patel (1996) stated that hope of spouses of critically ill

people was that the critically ill person's life after the hospitalization would return to normal. CCNs can influence close relatives' hopes by helping them appreciate the critical nature of the illness realistically, supporting their hope object, or helping them to focus on a new hope object (Patel 1996).

CCNs felt they were not honest when they did not think the critically ill person would survive but had to continue treatment because the physician had decided to do so. According to Cronqvist *et al.* (2004) CCNs described situations when they felt caught between their belief that a critically ill person should be allowed to die and their responsibility to carry out duties defined by the organization. Oberle and Hughes (2001) stated that physicians are responsible for making medical decisions and nurses have to live with those decisions. Studies (Viney 1996, Cobanoglu & Algier 2004, Zaforteza *et al.* 2005) have shown that communication problems with physicians can be barriers for CCNs in their advocacy of the critically ill persons with close relatives, which emphasize the need for intensive care to become a team effort. According to Takman and Severinsson (2005), when comparing Norwegian CCNs' and physicians' perceptions of the needs of close relatives in ICUs, there is a variation. This can lead to different ways of contacting themselves in encounters with close relatives in ICUs.

CCNs said it could be difficult to meet close relatives who were displeased about what had happened and they found it important to establish a good relationship also with close relatives who were dissatisfied. This can be seen as a way of establishing a caring relationship. According to Sundin (2001), a caring relationship is developed and grows deeper with every close meeting, as the parties become more familiar with each other, the relationship is further deepened. A caring relationship involves a unity in which the individuality and integrity of each are affirmed. Loss of individuality can make caring impossible. CCNs described how cultural differences between them and close relatives could be a problem. This can be compared with Burr (2001) who stated that CCNs in Australia had problems meeting the needs of culturally different close relatives. They felt frustrated when they had difficulty understanding other cultures. This highlights the need for nurses to have knowledge of different cultures to prevent this from becoming an obstacle to the forming of relationship.

CCNs wanted one CCN to take care of close relatives, especially during resuscitation. This is in line with Hallgrimsdottir (2000), who found that nurses felt that a member of staff should stay with close relatives. CCNs missed having a special person, such as an almoner or

hospital priest, to talk to close relatives. This is in contrast with Engström and Söderberg (2004) and Stubblefield and Murray (2001), where none of the participants would have preferred contact with an almoner or a hospital priest. They described friends and family members as their greatest support and also the staff. The question is whether close relatives would receive better support from someone else or whether the CCNs underrate their own competence. CCNs wished they could offer close relatives a better environment and the possibility sometimes to sleep over in the ICU. This is in line with Williams (2001), who stated that close relatives need comfortable environment and there are improvements to be made in this respect.

CCNs emphasized their need to discuss ethically difficult questions. Teamwork and mutual support of colleagues are important factors in dealing with difficult situations in ICUs (Wilkin & Slevin 2004). Reflection is considered an appropriate method for gaining an understanding of nurses' work (Socorro *et al.* 2001). Lantz and Severinsson (2001) show that group supervision with reference to close relatives' needs increases the CCNs' understanding of their role. Clinical supervision for CCNs can be interpreted as supportive in developing interpersonal skills and sensitive nursing practice (Lindahl & Norberg 2002).

CCNs missed having some follow-up on those people who had been critically ill and/or their close relatives. Crocker (2003) found that a multidisciplinary follow-up clinic provides a comprehensive service for people who have been critically ill in ICUs and their close relatives. From CCNs point of view, listening to people's experiences of the care they have received can encourage personal reflection on nursing practice which can in turn lead to professional and personal development (Strahan *et al.* 2003). Further research in this area is needed.

Limitations of the study

A disadvantage of the focus group discussion may be that some CCNs dominate the groups. This was not a problem in this study even though some CCNs talked more than others. There is a risk performing research within one's own field that one does not ask the participants for clarifications of their narration because it is easy to relate to and understand what they are narrating. We were conscious of our preunderstanding as nurse researchers and tried to interpret the data as open-mindedly as possible. The findings in this study cannot be generalized; they may allow people to understand their own experiences in a different and expanded way, i.e. the findings may be transferred to similar situations or people (Holloway & Wheeler 2002).

Conclusions

The findings of our study demonstrate that close relatives offer CCNs the chance to learn to know the critically ill person and they are a prerequisite for providing good nursing care that aims to meet the needs of the critically ill person. In the communication between CCNs and close relatives it is vital that a mutual understanding of the close relatives' situation is achieved and this is also necessary if CCNs will be able to support close relatives. CCNs and physicians need to improve their co-operation, especially concerning the planned care for the critically ill person with close relatives and how these relatives are to be given information. Dealing continually with ethical difficulties, without any possibilities to reflect or discuss those situations, makes it hard for CCNs to continue. CCNs want to improve their work to be able to give more individual nursing care to the critically ill person with close relatives. Those improvements would be of use both to the CCNs, who would be more satisfied with their work, and above all, the critically ill person with close relatives, who would get better nursing care.

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Contributions

Study design: ÅE, SS; data collection and analysis: ÅE, SS; manuscript preparation: ÅE, SS.

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Paper IV

**RE-VISITING THE ICU. EXPERIENCES OF FOLLOW-UP VISITS
TO AN ICU AFTER DISCHARGE:
A QUALITATIVE STUDY**

Åsa Engström MSc RN Phil Lic Doctoral student (1)

Staffan Andersson PhD MD Associate Professor (2)

Siv Söderberg PhD RNT Associate Professor (1)

1. Division of Nursing, Department of Health Science, Luleå University of
Technology, SE-971 87 Luleå, Sweden

2. Division of Medical Science, Department of Health Science, Luleå University of
Technology, SE-971 87 Luleå, Sweden

CORRESPONDENCE

Åsa Engström, Department of Health Science, Luleå University of Technology, SE-
971 87 Luleå, Sweden. Phone: +46 920 49 38 75, fax: +46 920 49 38 50, email:

asa.engstrom@ltu.se

Summary

The aim of this study is to describe how people, who have been critically ill, and their close relatives, experience a post-discharge, follow-up visit to the intensive care unit (ICU) that provided the care. There is a lack of studies from such a standpoint. The study design is qualitative. A total of 18 adults participated; nine had been critically ill and nine were close relatives, all made a post-discharge follow-up visit to an ICU in the northern part of Sweden. The study data was collected through personal interviews, conducted after the follow-up visit, using a narrative approach. The data were then subjected to qualitative thematic content analysis which resulted in four themes: receiving strength from returning together; making sense of the critical-illness experience; feeling grateful to have survived and the possibility of improving the care. People who had been critically ill and close relatives felt that returning together was valuable. Meeting the staff, with whom participants felt they had developed a relationship, made it possible for them to express their gratitude for the treatment and nursing care received, and to suggest improvements. The interviews revealed that follow-up visit was seen as an important way of learning what had happened and why during the period of critical illness.

Keywords: intensive care, follow-up visit, critically ill, experience, qualitative thematic content analysis

INTRODUCTION

People affected by acute, severe illness often need to be cared for in an intensive care unit (ICU). Life changes in many ways during and after critical illness both for the person concerned and for their close relatives. People who have been critically ill and treated in an ICU commonly experience amnesia or fragmented memories of their time in the ICU (Jones et al., 1998). Follow-up visits to ICUs, after discharge, for both those who were critically ill and their close relatives may be one way in which the former can recover the missing time and receive answers to questions (Griffiths and Jones, 2002). This study focuses on the experience of follow-up visits to an ICU from the perspective of adults who have been critically ill and their close relatives. The study is part of a qualitative inquiry into close relatives in the context of critical-care nursing.

Background

Several studies (e.g. Adamson et al., 2004, Hafsteindóttir, 1996, Maddox et al., 2001; Russell, 1999) have described how people who have been critically ill in an ICU often suffer from nightmares and anxiety. Some can remember their stay in the ICU, while others have only unpleasant fragmentary or delusional memories. Not knowing what happened during their time in the ICU is described as distressing. Johnson et al. (2006) demonstrated that people, when critically ill in the ICU, lost track of time and reality. They experienced disturbing hallucinations and nightmares, and felt their bodies were unfamiliar and unreliable. This highlights how frightening the experience of intensive care can be, and the importance of close relatives in making the ill person feel safe (Hupcey, 2000).

Hall-Smith et al. (1997) stated that people who had been critically ill in ICUs experienced vivid dreams, flashbacks, and stress in addition to profound tiredness and weakness. The

factors that predispose a person to experience amnesia after critical illness have not been clearly evaluated. People who are critically ill usually receive sedatives and analgesics during artificial ventilation, and these drugs are likely to influence their memory (Jones et al., 1998, Jones et al., 2000). Several studies (e.g. Jones et al., 2001, Magarey and McCutcheon, 2005, Roberts and Chaboyer, 2004) show that loss and fragmentation of memory have the potential to cause long-term psychological problems after discharge from the ICU. To have a person critically ill in an ICU is also a difficult situation for close relatives when, as it means living in uncertainty hovering between hope and despair (Engström and Söderberg, 2004). Even if it is positive development when the critically ill person can leave the ICU, it is described as a time full of uncertainty and anxiety for close relatives (Mitchell, 2003) and for the ill person (Odell, 2000). When the ill person is discharged close relatives might also feel burdened by their impairment (Johnson et al., 2001).

There is a need to talk about the ICU experience and the memory loss, otherwise recovery at home may be difficult both for the person who has been critically ill (Jones et al., 2003) and for their close relatives (Hall-Smith et al., 1997). According to Jones et al. (1998) both parties need the opportunity to talk about the illness and the time spent in the ICU with the staff who were involved in the care. Crocker (2003) suggests that people who have been critically ill need explanations and follow-up visits, after discharge, to the ICU to put their experiences into context. Returning to the ICU and meeting the staff again can also be valuable for close relatives (Engström and Söderberg, 2004). According to Griffiths and Jones (2002) follow-up visits to ICUs can improve the quality of recovery from critical illness. Other studies (e.g. Cutler et al., 2003, Corrigan et al., 2007, Löf et al., 2006) emphasise the necessity of some form of follow-up service for people who have been critically ill. Bäckman and Walther (2001) suggest that the narrative of the ill person's ICU stay in the form of a diary together

with a follow-up visit to the ICU, might help them to understand their ICU stay and their illness.

In summary, we have found that studies concerning how people who have been critically ill, and their close relatives, experience a post-discharge follow-up visit to an ICU are lacking. The studies found suggest that such follow-up visits to an ICU can help people who have been critically ill to understand what has happened and to discuss their memories. However, these studies are mostly presented from the perspective of the staff. This study is presented from the perspective of people who have been critically ill and their close relatives. Incorporating the knowledge gained from their experiences will make it possible to meet the needs of people who are or have been critically ill and their close relatives.

The aim

The aim of this study was to describe post-discharge follow-up visits to an ICU as experienced by both people who had been critically ill and cared for in an ICU and their close relatives.

METHOD

The post-discharge follow-up visit

The post-discharge follow-up visits were made during 2004-2006. One critical care nurse was responsible for planning the visits. The critical care nurse and the physician who were most involved with the critically ill person in the ICU were scheduled to participate in the follow-up visit with the person who had been critically ill and their close relatives, if any. A room was reserved for the visit where all could participate in peace and quiet. The participants were

requested to bring their personal written diary from their stay in the ICU, in which nursing staff and close relatives had written about the ill person's situation and events of the day. The person who had been critically ill and their close relatives were encouraged to talk about their experiences and the critical care nurse and the physician had the opportunity to answer their questions. The critical care nurse and the physician asked specifically about strange, hallucinatory and delusional experiences since these experiences are common (cf. Griffiths & Jones, 2002). The rooms and equipment used when the people were cared in the ICU were shown to them, if they were in use, they were shown similar equipment.

Participants and procedure

The inclusion criteria for participation in the follow-up visit were that the person had been critically ill, on respiratory treatment for at least 24 hours, and cared for in an ICU for at least 72 hours. Twenty-three people who were discharged from the ICU and the hospital were offered the possibility of a follow-up visit to the ICU with their close relatives, about six months after leaving the ICU. Fifteen people who had been critically ill came to the follow-up visits together with one or two of their close relatives. In one follow-up visit, the person who had been critically ill did not participate, but his close relatives did. One critical care nurse and one physician participated in all but three follow-up visits. In the three exceptions no physicians participated. Letters were sent to fifteen people who had been critically ill and their close relatives who had attended the follow-up visits, where they were offered the opportunity to participate in an interview about their experiences of revisiting the ICU. Eighteen people answered that they were interested in participating, nine people who had been critically ill and nine close relatives. The people who had been critically ill, eight men and one women, were aged between 40-74 years (md= 63) at the time of the interviews. The close relatives, one man and eight women, were at the time of the interviews aged between 37-64 years (md= 52). The

medical diagnoses for those who were critically ill were cardiac arrest with hypothermic treatment (n=3), stroke (n=1), attempted suicide (n=1), postoperative care after aortic aneurysm (n=2), ileus (n=1) and adrenal gland cancer (n=1). Two of these people had been in regular contact with a counsellor or a psychologist since their stay in ICU. Close relatives to those who had been critically ill were: wife (n=4), parents (n=2, one mother and one father), personal assistant (n=1) and daughters (n=2).

Data collection

Personal audio-taped interviews using a narrative approach (cf. Sandelowski, 1991) were conducted with the participants from 2005-2007. Each participant was interviewed separately except one, who was accompanied by her personal assistant to help her communicate her experiences. The participants were asked to narrate their experiences of the follow-up visit to the ICU and clarifying questions were asked e.g. How did you feel then? Can you give an example? The interviews lasted for approximately 35-120 minutes and took place in a quiet room in the participants' homes (n=15) at the interviewer's work place (n=2) or in a public building near their home (n=1), in accordance with their wishes. One participant was interviewed by phone as she lived abroad. The interviews were then transcribed verbatim and the transcripts were reviewed for accuracy by the first author.

Ethical approval

The participants were informed about the general nature of the study by letter before the interviews started. They were contacted by phone and appointments for the interviews were made. The participants were reassured that their participation was entirely voluntary and that they could withdraw from the study at any time. They were guaranteed confidentiality in the presentation of the findings. The Regional Ethical Review Board approved the study.

Data analysis

The interview texts were analysed using qualitative thematic content analysis. The goal of qualitative content analysis is to provide knowledge and understanding of the phenomena being studied (Downe-Wamboldt, 1992). Each interview was read through several times in order to gain a sense of the content. The whole text was then read to identify meaning units, guided by the aim of the study. The meaning units were condensed and sorted into categories related to their content. Those categories that were related to each other were subsumed into four themes, i.e., threads of meanings that emerged in the categories (cf. Baxter, 1991).

RESULTS

The analysis of the interviews resulted in the following four themes: receiving strength from returning together, making sense of the critical-illness experience, feeling grateful to have survived and the possibility of improving the care. In the results the participants who were critically ill are referred to as the critically ill person/people. Participants who were close relatives of people who had been critically ill are referred to as close relative/ relatives. When the result concerns both the critically ill people and their close relatives they are referred to as participants.

Receiving strength from returning together

Participants said that it felt good to return to the ICU together; it was easier to remember what they had been told when they made the follow-up visit together. Critically ill people found it was safer to make the follow-up visit with someone who had been present in the ICU and who remembered various events, as they were a little afraid of being asked questions they might not be able to answer and also that they might not know where to go. For the close relatives

the follow-up visit was a way of supporting the person who had been critically ill. Two close relatives described how their son, who had been critically ill, did not want to participate in the follow-up visit; they went in order to be able to answer his questions if or when they should arise. Close relatives said they wanted to talk about what had happened to them after the period in the ICU, and how the critically ill person was when he or she was not unconscious or confused.

When he was ill he was so confused and a bit aggressive and mean and that isn't my dad...I thought it was great, especially because I saw my father in this situation, where he could meet the ICU staff who had nursed him when he was so critically ill and they could see what sort of man he really is and he could answer their questions...it was positive for me too, because we felt we were valuable in this. (close relative 2)

She was present and was involved in what we were told, it was an advantage because then she was informed and she could also help me to remember things I might forget, together we remember a bit better... you can say she was like a support for me to remember better what I had asked about and what answers I got. (critically ill person 9)

Making sense of the critical-illness experience

The follow-up visit was described as one way of getting to know what had happened and why. Critically ill people said that other ways of getting to know about that had been to speak to their close relatives; to meet other people who had cared for them; to return to the place where they were critically ill; to read their personal written diary and to see photographs taken while

they were critically ill. Those critically ill people who had a diary written during their stay in the ICU took it with them to the follow-up visit. Looking at pictures and reading the diary from the time when they were critically ill was described as valuable because they got a picture of what had happened and how ill they had been. They thought it was hard to read about how much close relatives cared and worried about them and critically ill people said they cried when they read some parts of their diaries. Close relatives also appreciated the diary and also found parts to be hard to read.

In the beginning I did not read the whole diary it was so hard but at the same time it was comforting... I cried to myself when I read it in the beginning and then it became interesting and finally I thought it was good...my family had written a lot and those parts of the diary were really something special... (critically ill person 2)

Participants appreciated seeing once more the specific room where the critically ill people lay in the ICU and some of the equipment. Critically ill people were pleased to return to the ICU when they felt their mind was clear. They said they did not remember the spatial experience of the ICU; it was only when they returned to it that they understood what it looked like and how the equipment worked. Critically ill people said they did not recognize the staff or they only recognized a few of them. One critically ill person said he did not remember anything from his stay in the ICU, but he recognized the voice of a nurse when he heard her talking during the follow-up visit. There were also descriptions of recognizing different sounds when they heard them again e.g. from monitors and ventilators.

It gave me reference points; I mean I missed the references, what I had experienced as huge resumed normal proportions when I saw it again in a new way... it was this far from the corner to the next corner, two and a half metres, not two kilometres, and all these pieces fell into the right place. It was very important for me to see where I had been. (critically ill person 3)

Critically ill people had experienced hallucinations or nightmares, some saw demons while they were seriously ill and they had talked about this during the follow-up visit. The dreams felt real and were mostly frightening. It was good to talk to the staff, who knew that hallucinations and nightmares during ICU treatment were common and that they had not thought the critically ill people were mad when they talked about these experiences. Getting to know that these phenomena frequently occur in critically ill people and hearing possible reasons was described as confirmation and valuable feedback. One critically ill person described the follow-up visit as a way in which to prepare for his next operation and period in the ICU, but he was afraid of experiencing terrifying hallucinations again. Close relatives said they did not have many unanswered questions; they knew what had happened when the person became critically ill, but during the follow-up visit they felt they got answers to why it happened. They described it was helpful for them to have this possibility, as otherwise they would have been left alone with the critically ill person's thoughts and questions about the time they spent in the ICU.

It was mostly my husband who asked questions... he told them he had seen a lot of flies on the ceiling, and he thought that the nurses were upside down and things like that, and they explained why and how it was and about the drugs which made

him experience things that hadn't really happened... they explained things he wondered about. (close relative 3)

Feeling grateful to have survived

Participants felt fortunate that the critically ill people had survived their serious illness and mentioned different circumstances which they thought had saved the ill peoples' lives. They said that returning to the ICU revived memories from the time they had spent there, it had been a difficult time, and it felt good to return and see where the person who had been critically ill had, in a way, come back to life. Meeting the staff again was felt as to be an important part of the follow-up visit, giving them a chance to express their gratitude for their work. Participants valued the opportunity to return to the ICU and the fact that the nurse and the physician had taken the time to meet them. Close relatives felt they had developed a special relationship with one or more of the staff, those who were the most involved in the nursing and treatment of the critically ill person, and they described it as nice to meet them again.

That was really one of the nicest things I remember at all, coming back and knowing he had been so close to death and survived it...there was also the social part that the busy physician and nurse took time which showed that for them the human relationship also meant something... (close relative 5)

The possibility of improving the care

Participants described that during the follow-up visit they had been asked to suggest improvements that could be made in the care provided in the ICU. One close relative said she had been asked to participate in the care of her, critically ill son, who was about 20 years old,

but she had felt frustrated as it could be embarrassing for her son, and they had talked about that during the follow-up visit. Participants said that they had mentioned that they did not know which of the physicians was responsible for what. One critically ill person described that he had told them that it was hard to know what time it was when he was in the ICU and whether it was day or night. Another critically ill person said he had felt panic during the nights in ICU as he thought he was going to die and had suggested that the staff should be better at trying to calm down the ill person. Critically ill people found it difficult to suggest improvements within the nursing care when they did not clearly remember the time they spent in the ICU. The participants described how they were disappointed when another physician or intensive care nurse, instead of the one who had mostly had treated the ill person, participated in the follow-up visit. In those visits where no physicians were present the participants said it was very important to meet the nurse who had been with them most in the ICU and who was aware of different events that had happened during their stay in the ICU.

For me it's a sign that they are interested in knowing what happened then... what I experienced and if they can make some improvements... but like I said it's difficult being critical or praising them when I don't know so much about it... I can't distinguish between those weeks. (critically ill person 1)

Close relatives said they had felt that the room intended for close relatives in the ICU was too small and sometimes it had been hard to share it with others. They described most of the staffs' encounter during their stay in the ICU as good but they also mentioned examples of meetings that were not so good, and they had talked about that during the follow-up visit. Participants also had ideas and questions they had not told the staff about during the follow-up visit as they thought that everything else had been so good, or they had forgotten.

The room for relatives, it's a pity it's just one, it actually is, just we were six people and there were others there too... We told her [the nurse] that and she said there are many others who have said that too, because it's so important to be able to shut the door and be alone for a while. (close relative 6)

... it was a chance to bring up both good and bad things that happened and I mentioned this physician ...he stood there staring at us saying: I hope they have told you it isn't certain he will ever wake up again ... that hit me very hard...later he [her husband] started to cough as he was irritated by that tube and the nurse wanted to take the respirator away but had to ask that physician and he came back saying: How should I know about that? I had to bite my tongue not to say: Who the hell should know if you don't... but all the others they were fantastic with us I really think they were... (close relative 8)

DISCUSSION

The aim of this study was to describe post-discharge follow-up visits to an ICU as experienced by people who had been critically ill and cared for in an ICU and their close relatives. The results showed it was valuable to return together and to receive explanations for what had happened during the participant's stay in the ICU. Meeting the staff who had been mostly responsible for the care of the ill person offered them the chance to express their gratitude for the treatment and nursing care, and also for their survival. They appreciated meeting again those members of staff because the participants felt they had developed a relationship with them. The follow-up visit was also seen as offering them the possibility of discussing the treatment and nursing care and of suggesting improvements. As they made the

follow-up visit together, the person who had been critically ill was supported by their close relatives. According to Edlund (2002) the inner duty to serve another person is sacred and is performed in being able to help someone. For close relatives it was important to show the staff what the person who had been critically ill was like when they were not critically ill or confused. Engström and Söderberg (2004) show it is difficult for close relatives to see the critically ill person confused and hard to contact; one way of experiencing dignity is to feel tidy and behave appropriately which the critically ill did not (Edlund, 2002). In this study people who had been critically ill wanted to have their close relatives present to feel safe and to know what to say. This agrees with Bergbom and Askwall (2000) who describe close relatives as a lifeline for critically ill people in ICUs. Engström and Söderberg (2007) show that people who have been critically ill feel that their close relatives provide the motivation for them to continue the struggle; they want close relatives to stay near them in order to feel safe.

The follow-up visit offered the possibility of getting to know what had happened and why. The need to know is important and those who have been critically ill spend an enormous amount of energy piecing together information as they go through the process from not knowing to knowing (Hupcey and Zimmerman, 2000). Fredriksen and Ringsberg (2007) show how difficult it is to live in a situation in which many factors appear to be without meaning and to feel at the same time that meaningfulness is a help in understanding a situation. Participants in this study asked themselves and others why they had fallen critically ill. According to Johannisson (1992) the question 'why me' and the experience of unfairness led to feelings of despair, and a desire for the suffering to be fairly distributed. There is a need to feel that one's suffering has a meaning, a story and a coherence. Söderberg et al. (1999) stress

the importance of understanding and finding explanations when stricken by illness; in seeking and receiving explanations and understanding the ill person can obtain relief.

It was experienced as confirmation when, during the follow-up visit, participants heard that it was common to experience hallucinations while critically ill. Edlund (2002) noted that to be considered credible is important for self-esteem and self-respect. Johnson et al. (2006) found that critically ill people experienced hallucinations and dreams as awful dreams and unreal fantasies. Sharing their accounts was helpful, as it reduced the impact of this aspect of their experience. Chaboyer and Grace (2003) show that talking to other people who have been critically ill, their close relatives and staff, helps to normalize the experiences following the stay in the ICU. It is described as comforting to know that others have also been confused or have tracheotomy scares, or, as a close relative, to talk to others about the time during and after the ill person's stay in the ICU. The sharing of illness experiences seems to reduce the suffering (Johannisson, 1992).

Studies (Bergbom et al., 1999, Combe, 2005, Roulin et al., 2007) show that the use of a personal written diary in the ICU is a useful tool for filling in some of the missing time following intensive care. This study showed that reading the personal diary as a part of the follow-up visit was appreciated; it was way to understand what had happened during the participant's stay in the ICU, but it was also difficult to read. This has not been shown in previous studies. People who had been critically ill remembered the room they lay in the ICU as large and found in reality it was small. Fredriksen and Ringsberg (2007) emphasize that the critically ill person's experience of the room in an ICU is affected by the position from which the body senses the room; strong lights, noise, technical equipment and procedures, being

seriously ill and lying in a horizontal position mean that the experience is filled stressful and hard to comprehend.

During the follow-up visit the participants in this study could express the gratitude they felt for the work of the staff in the ICU. Parker (1999) states there is a need to express your admiration and gratitude when you feel that you have been close to death and survived with help of nurses and physicians. In this study the follow-up visit was described as providing an opportunity for the participants to give their view on the care and possible improvements that could be made. Edlund (2002) states that when others pay attention to what a person has to say it confirms that he or she is worth something and this gives rise to a feeling of having dignity.

In this study the encounters with the staff in the ICU were described almost exclusively as good, but there were examples of the opposite. When relationships with staff are good, close relatives are better able to bear their experience, but one troubling relationship with someone on the staff seems to over-shadow positive connections with others (Eggenberger and Nelms, 2007). Our result showed that participants did not always mention things that could be improved because everything else had been so good or they had forgotten to mention them. Sørli et al. (2006) show that although ill people in an acute care ward are satisfied with the treatment and care, they do not consider all the factors optimal. They explain these as something that just has to be accepted. Therefore, staff should not be complacent when people express satisfaction, as this can result in a loss of focus on their vulnerability and on their reflections about the care given.

Limitation

This study has limitations as the people who chose to participate were a selected group because they might have been those who needed to talk about their experiences and perhaps had a positive opinion about the follow-up visit and participating in the study. We do not know why some people who were offered a follow-up visit and the opportunity to participate in this study chose not to do either.

Conclusion

Nine people previously nursed and treated in an ICU, and nine close relatives participated in this study. Research has previously suggested that post-discharge follow-up visits to ICUs are valuable for people who have been critically ill as they help them to understand what has happened and allow them to talk about their memories of their stay in the ICU. The results of this study agree with earlier findings. This study also shows the value of a diary for filling in memory gaps and comprehending ones' significance. This study, furthermore, shows that people who had been critically ill appreciated being able to return to the ICU together with close relatives as it feels safer. The follow-up visit offers them the possibility to talk about what happened after their stay in the ICU, to receive explanations and to discuss their experiences. It is important to meet the ICU staff again, especially those who were most involved in the nursing and treatment of the ill person. This gives them an opportunity to express their gratitude for their work, but also their opinions about the care provided and to suggest improvements. The follow-up visit is just one of many pieces in the puzzle of getting to know what had happened and why during their critical illness, but this piece seems to be important for all involved.

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