

## EMPIRICAL STUDY

**Interaction with potential donors' families: The professionals' community of concern—a phenomenological study**

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**Abstract**

The aim of this paper was to explore the health professionals' experiences and gain a deeper understanding of interaction with families of critically ill or traumatized patients with severe brain injuries. The methodological approach was qualitative and phenomenological. Data were collected through participant observation and in-depth interviews with nurses, physicians, and chaplains working in two ICUs in a Norwegian university hospital. A thematic analysis was used for analyzing data. Two main themes emerged from analysis: *Patient oriented even when present* and *Family oriented even when absent*. Each main theme is divided into two sub-themes. The themes appeared as phases in an interaction process. In the two first phases the interaction may be characterized as *Alternating between being absent and present* and *Following up and withholding information* and in the two last phases as *Turning point and changing focus* and *Partly present when waiting for death*. The findings are in the discussion illuminated by the phenomenological concept of concern. Concern is visible as care, and the distinction in care between “leaps in” and “leaps ahead” and “ready-to-hand” and “unready-to-hand” are topics in the discussion. Because of the complexity of caring for both patient and family, the situation demands efforts to relieve nurses in particular, during the most demanding phases of the process.

**Key words:** *Health professionals, experience, organ donation, interaction, family, interpretive phenomenology*

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**Introduction**

Several studies have pointed out that caring for potential donors and their families is a challenge. International studies found that identification of a potential donor was made under conditions of prognostic ambiguity (Day, 2001), and that a shift in care from the brain-injured patient to the maintenance of his organs took place (Day, 2001; Sadala & Mendez, 2000). This shift required technical, scientific, and other skills that were in conflict with traditional nursing care (Sadala & Mendez, 2000). Nurses experienced conflicting meanings related to the ambiguity of the proclamation of death, the family's distress when confronting the sudden tragedy and when complying with the request, and the care related to outcome (Pearson, Robertson-Malt, Walsh, & Fitzgerald, 2001). Numerous studies emphasized the nurses' central role in caring for

the family (Coyle, 2000; Frid, Bergbom-Engeberg & Haljamäe, 1998; Gill & Hulatt, 2000; Hibbert, 1995; Pelletier, 1993; Smith, 2003; Smith-Brew & Yanai, 1996; Watkinson, 1995), but also stated that such care required advanced knowledge, skill, and expertise (Coyle, 2000). A study among physicians reported that interaction with families was difficult due to the sensitive nature of the situation (Sadala, Lorencon, Cercal, & Schelp, 2006). According to Williams et al. (2003), discussing severe brain injuries, brain death, and organ donation with families is a specialized form of end-of-life decision making and care in ICU. A lack of training in communicating with families is reported (Pellereiaux et al. 2008; Pont Castellana et al. 2008), but also improved self-efficacy after attending educational programs (Blok et al. 2004). Literature also revealed that American physicians were not routinely

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involved in organ donation (Essman & Lebovitz, 2005). This stands in contrast to Norwegian practice, where physicians play a central role in informing and approaching families for organ donation (Alnes, 2000, 2002).

Although the activities of organ donation and transplantation are well established in Norway, few studies have been carried out in this area. In a study of attitudes to the use of organs from deceased people, Solheim, Brattebø, and Wisborg (1993) found that 71% of the population would accept that a person in their family became a donor for organ transplantation. Alnes (2000) has studied ethical, communicative, and emotional problems related to organ donation. Among others, the findings revealed that in cases of severe brain injuries or “sudden death,” the physicians’ caring in the early stages included patients waiting for organs. Hence, the announcement of the bad news had extended consequences. The physicians’ explanations and the way the question of organ donation was presented were important elements of the conversation with the relatives. A study related to families’ experiences (Orøy, 2002) reported that the professionals’ approach was of the greatest importance; not only when raising the issue, but also before and after the issue was raised. A study among nurses highlighted the need for collaboration and mutual understanding in the treatment team, and emphasized knowledge and professional competence as central in communication with the families (Meyer & Bjørk, 2008). The aim of this study was to explore health professionals’ experiences and gain a deeper understanding of interactions with families to critically ill or traumatized patients with severe brain injuries.

## Methodology and methods

An interpretive phenomenological approach was used in the search for meaning in the participants’ experiences. Based on phenomenological and hermeneutical philosophy, this approach offers a method of interpretation that uncovers human concerns and practices taken for granted and central to being and dwelling in the world (Benner, 1994; Benner, Tanner & Chesla, 1996; Benner & Wrubel, 1989; Dreyfus, 1991; Heidegger, 1962). By engaging in dialogue with the text, the researcher seeks to understand the experiences from the participants’ points of view. The aim is to study the phenomenon in its own terms, which requires critical reflections on the methodological strategies, personal knowledge, and social context that influence our understanding. This also involves scholarly reading, questioning, comparing, and imaginatively dwelling in the text. The phenomenon and its context frame

our understanding and the interpretive assumption is that the human world can never be spelled out completely (Benner, 1994). “Human worlds are historical, contextual and multifaceted, and are only grasped under finite and situated aspects” (Benner, 1994, p. 100). In realization of the contexts’ significance in understanding the participants’ experiences, the first author spent 4 weeks as a visitor in the ICUs to become familiar with the environment and the health professionals prior to the data collection. In that way she enabled herself to contextualize the data.

### *Design and data collection*

The study was designed as a combination of participant observation (Fangen, 2004; Wadel, 1991) and in-depth interviews (Kvale, 1997) with nurses, physicians, and hospital chaplains working in two ICUs in one Norwegian university hospital. Data collection took place from April 2006 to October 2007. Nurses or physicians notified the researcher when they had a potential situation for the study. The main focus for participant observations and interviews was health professionals’ interaction with families of critically ill or traumatized patients with severe brain injuries. Focus for observations and interviews is described in Table I.

During data collection, the researcher was involved in 12 situations. Observation time in each situation varied from 12 to 94 h, and the researcher spent a total of about 350 hours in ICU. Field notes were taken from each situation, and in-depth interviews were carried out with 16 nurses, 12 physicians,

Table I. Focus for participant observations and interviews.

Focus for participant observation:
How do the health professionals interact with the family during their stay in ICU?
How do they follow-up family?
How do they prepare the family for possible consequences of the situation?
How do they announce the patient’s death?
How do they present the option of organ donation?
How do they arrange for farewell?
How do they follow-up family afterwards?
How do they collaborate with each other?
Theme for in-depth interview:
Demographic data of the participants
Experience related to the situation
Experiences related to organ donation in general/particular
Experience related to interaction and collaboration
Experience related to interaction and environment’s influence (time, space)
Values in interaction with family
How do the health professionals prepare themselves for interaction with family?

and 4 hospital chaplains associated with presenting the option of organ donation or with the donation process. One nurse, one physician, and two chaplains were interviewed twice and one physician four times, as they were involved in two and four situations, respectively. The interviews lasted from 25 min to 2.5 h, were tape recorded, and transcribed verbatim. Demographic data of the participants are presented in Table II.

### Analysis

A thematic analysis (Benner, 1994; Van Manen, 1990) was used to identify meaningful themes, patterns, and concerns related to the subject. To grasp the meaning of the participants' experiences, each situation was approached as a whole, and the interpretive analysis was a back and forth process, between the parts and the whole in the field notes and the interviews. The texts from field notes and interviews were initially read and interpreted one by one and then as a whole. First, the notes from each observed situation were read for global understanding. This reading brought the researcher "back" to ICU and the tragic event with all its implicated parties. An atmosphere of severity was recalled and the participants' verbal and non-verbal "voices" and situated actions emerged, creating a sense of the totality of what was going on. Next, preliminary themes were selected and marked in one margin, and interpretive questions and comments were written in the other. Following this, similarities and differences were searched for and clustered into main themes and sub-themes. The same steps were used in analyzing the interviews. Finally, themes from observations and interviews were compared, and patterns of meaning appeared as a whole. Two main themes with four sub-themes emerged. The themes appeared as phases in a process, visualizing the health professionals' experiences of interaction with families during life-threatening illness or trauma and organ donation.

### Ethical considerations

The study was approved by The Regional Committee for Medical Research Ethics. License for collecting data was obtained by The Privacy Ombudsman for Research. Dispensation from professional secrecy was given by The Ministry of Health and Care Services. Permission to do the study in ICUs was granted by the Chief Physicians in the two participating units. The study was also presented to physicians, nurses, and chaplains working in the units, and informed consent was obtained from all health professionals and families involved. Written informed consent from the families was obtained by physicians or nurses involved in the situation. The families consented on behalf of the unconscious patient and gave access to data about the situation.

### Findings

Findings revealed that health professionals' experience of interaction with families were contextual, influenced by the patients' condition and progress, time to clarify prognosis, families involved, and collaboration in the treatment team. To give a picture on how this is going on, a case is used as an introduction. The chosen case is based on observations and interviews from one situation. Despite all situations being unique, interactions with the family in the following example shows similarities with interaction in other situations.

#### Case: Preparing a family for death

A young man had been seriously injured in an accident and sent to ICU. His mother and several family members were present. They were all profoundly saddened by the tragic accident. The CT scan showed severe head and brain injuries. Intracranial pressure (ICP) was high, and he received medical treatment aimed at keeping the pressure down. The physician explained that the

Table II. Demographic data of the participants.

No	Profession	Age	Experience in ICU	Experience with organ donation
8	Reg. nurses	27–46 yr	$\frac{3}{4}$ yr–16 years (mean: 4.7 yr)	First time: 4 Second time: 1 Third time: 2 Several times: 1, but mostly in parts
8	Critical care nurses	35–48 yr	5–15 years (mean: 7.2 yr)	First time: 1 Third time: 1 Several times: 6, but mostly in parts
8	Head physician	40–50 yr	9–18 years (mean: 14.6 yr)	Several times
4	Senior resident	30–40 yr	2–4 years (mean: 3.3 yr)	Several times, first time active involvement 1
4	Chaplain	50–60 yr	4–6.5 year (mean: 5 yr)	Several times

situation was critical and prepared the family for that he might die.

The patient remained more stable than expected during the first few days. Neurosurgeons, ICU-physicians, and critical care nurses collaborated on the treatment and care for the patient and his family. Although the professionals' main focus was on the patient and giving him the best treatment available, they also followed up his relatives with information. They were initially told that the patient might die, later that he was more stable than expected, but that the situation was still critical and things could happen. The family alternated between hope and despair.

However, after some days ICP started to increase along with other changes. The health care providers discussed the situation and despite favorable experiences with similar patients things did not look reassuring. The mother who immediately saw the changes, wanted to know what could be done if the ICP continued to increase. When she was told that they might take another CT, her anxiety rose. The CT-scan was performed, and the neurosurgeon informed the mother that the increase in ICP was a possible sign of a swelling of the brain, a bad sign. The mother struggled to find words but finally said "What can we do? What will happen?" The physician explained in brief terms that the high ICP would probably destroy her son's brain and with no blood circulating to the brain he would die—become "brain dead." In this event, the professionals had to present the awful question of whether the family was willing to donate the patient's organs. The mother spontaneously offered "I really do want to donate his organs. I have thought about it. He can save other people's life, can't he? To me, this is not such an awful question. I want to say yes to donation." The physician praised her positive attitude, but emphasized that her son was not yet dead and that they wanted to give him the best treatment until there no longer was any hope.

The next morning a new meeting was arranged with the whole family. When the physician mentioned organ donation, the mother told him that she had already consented to donation. At this point, the family just wanted to know about the further plans. Everything was changed that morning, and the atmosphere may be characterized as a mixture of resignation and grief without hope. The patient's condition deteriorated further, and the physician carefully informed about the latest changes and stated that the patient was now dead. At these words the family members became silent, before they responded emotionally. For 7 days they had waited in uncertainty. They had moved from despair to hope and back again. The last message indicated

that the fight was over. Some of the family members wanted to see the young man one last time. Only the mother wanted to return after the donation.

Now the focus of treatment and care was changed. The assumed brain death was confirmed by cerebral angiography, and the patient was declared dead. The donation team arrived and removed organs for waiting recipients. Back in ICU the mother's final encounter with her deceased son was emotional. The nurse gave her the time she needed. She wanted him dressed in his own clothes and so they did. Finally the nurse offered her coffee and a last conversation.

#### *The dual interaction process*

This case shows how health professionals supported the family in coming to terms with the possibility of death and organ donation during life-threatening head and brain injuries.

From analysis, two main themes and four sub-themes appeared as phases in a dual process, which visualized a meaningful pattern in interaction with families. As the clarification of the patient's prognosis took more time in the referred situation than in the others, the process became more visible and also easier to grasp. In other situations the process was more condensed and not as evident. In the process' various phases the family alternated between being the focus of and the background for the professionals' attention. The process has two aspects, not only regarding the focus on interaction with families but also related to the content of such interaction. In the following we will describe this dual interaction process as recognized across all situations. Similarities as well as variations from the observed situations and interviews will be exemplified.

#### **Patient oriented even when present**

During the two first phases, interaction may be characterized as patient oriented and dominated by tasks or information related to the patient's condition.

#### *Alternating between being absent and present.*

The professionals' main focus was to save the patients' lives. Before admission to ICU, the patients had received the initial life-saving treatment, but were still in a critical and unstable state. The professionals had several tasks to carry out related to treatment and follow-up observations. This required concentration and watchfulness. Interaction with families may be characterized as alternating between being absent and present.

Despite the main focus being on the patient, the professionals were aware of the meaning of information and of being present for the family. Once the patient was medically stabilized, the responsible physician offered information about the patient's condition. The formal information was usually given in a "family-room." For the sake of following up the family, the nurses preferred to be present. The physicians' information was related to facts about the patient's clinical condition, and in most cases the patient's condition was so critical that the family was prepared for the possibility of death. The word death was not always used, but uncertainty related to outcome was emphasized. The families were unprepared for and deeply shaken by this message, and the professionals described their reactions with sympathy and understanding, but also as challenging:

They left the room while the information was given . . . first the daughter, and later her boyfriend and the youngest brother. For me this was hard, because they went into the corridor where everybody else was sitting . . . they had no other place to go . . . I was in doubt, whether to follow the family or listen to the physicians' information . . . In a way, I had to be present to hear what they said . . . it's about the further follow-up . . . you can repeat and explain (to the family). (Nurse)

The nurse further said it was hard to know what to prioritize. On the one hand there was a critically ill patient and on the other, an extremely frightened family. The nurses had to somehow divide their attention. They were primarily there for the patient, and they always had to prioritize him or her.

Following the initial information, the relatives were offered a place at the bedside. Even though they had been prepared for the patients' condition and all treatment and recovery related technology, this became a challenging encounter and they did not remain by the bedside for long. A nurse from the referred case described the visit in this way:

In the beginning it was hard to get to know the family. Several family members were present and they visited for a short time only . . . My main focus was on the patient. There were a lot of tasks to perform, and at that time we didn't know how severe the injury was. We worked according to the steps in the Protocol (for Head and Brain Injuries), we were busy and I just couldn't sit down to talk. (Nurse)

While this nurse told about a busy time and that she could not sit down to talk with the family, another emphasized they were two nurses and that she

therefore could spend time with the family. Due to the difficulty of caring for both the patient and the family, most nurses reported a need for two nurses to be present in such situations. This was, however, not always possible.

#### *Following up and withholding information*

After the initial treatment the health professionals reported a need for time to clarify the patients' prognoses, a process usually lasting from some hours to a few days. For the patient in the referred case, clarification required 5–6 days, which is more than usual. In other cases the prognosis was clarified with the first CT-scan or the patient's condition would sometimes vary before clarification. The main focus of interaction during this phase was still patient oriented, marked by sensing the family's needs, and following up and withholding information.

The nurses gave priority to the family when they visited. Despite the patient requiring their concentration and watchfulness, they were polite, friendly, and sensitively present. When they saw that family members cared for each other they did not intervene, but just observed the situation or gave indirect support. However, sometimes the relatives were so marked by the tragic events that they neither initiated conversation nor visited the bedside, spending most of the time in the family room. This was challenging, especially when they were alone:

It was hard. I could not get to him . . . he withdrew from the situation. The only person I was able to reach was the youngest daughter . . . Perhaps, if there has been more time . . . But in this situation . . . I had to deal with him only as the patient's husband; and in addition some practical information. (Nurse)

When this happened, the nurses tried to get in touch when the relatives visited, and if they got less or no response, they gave space for privacy, and emphasized their availability. The nurses' main position was by the bedside and, with the exception of attending the physicians' conversations with the families in the family room, they rarely initiated interaction outside ICU.

Nurses and physicians alike were aware of the significance of giving the family information. While the formal information was given in the family room by the physicians, informal and follow-up information was given by the bedside, as a rule by the nurses:

Several times the family asked; what do you think, how does such a situation usually progress? Again and again I had to repeat, I don't know. That was

true, we really didn't know... In such a severe situation it is wrong to give the family hope or false expectations... Objective data like BP and ICP are all we have to describe his condition. (Nurse)

While some nurses were afraid of giving false hope or expectations, other worried about the families understanding of the situation. One nurse told that the family left for home after the initial information. As the patient's condition was unstable and critical, they had to phone the family several times before they decided to come.

The physicians went to and from and followed up the patient on daily rounds, usually when the family was absent. They were, however, available for information and offered factual information on the uncertainties related to outcome, but withheld information about the tests related to organ donation and the fact that they had a potential donor in mind. However, when the patient's condition changed, the families were gradually informed about the changes. Intensity in conversations depended on the progress of the patient's condition and time was of crucial importance.

### **Family oriented even when absent**

Interaction during the last two phases was family oriented and dominated by respect and tacit understanding of the families' situation.

#### *Turning point and changing focus*

The turning point in a patient's condition occurred when clinical signs or changes showed improvement or a probable progression to brain death. If his condition improved, he was transferred to the ward. In most cases, however, the patient's condition worsened and the interaction was focused on the timing of bringing up the subject of organ donation and finding out where the family stood on this issue. Presenting organ donation as a possibility indicated a turning point also in the interaction with families, and the main focus of the professionals' interaction shifted from the patient to the family.

The subject of organ donation was brought up in connection with information on the patients' clinical condition and development. Brain death was usually presented when it appeared with high probability and not as a fact. The issue was generally presented by the neurosurgeons, who in most cases used a step-by-step strategy in approaching the family. This stepwise approach to information gave professionals and families alike time to sort out the situation. However, the patient's prognosis was in some cases so serious that the subject was introduced along with

the initial information. Some physicians stated that timing the subject of organ donation was never easy. They were afraid of causing the family harm. As one of the physicians said: "I'm always afraid of causing harm by presenting the option too early." Sometimes the patient's condition unexpectedly "improved" after the subject was introduced, a situation that was followed up with information by the physician. The family found this to be quite a traumatic experience and some responded negatively to being presented with the issue of organ donation before the patient's condition was clarified.

In most cases the physicians asked for the patient's view on organ donation and wanted a decision in accordance with his or her attitudes. The nurses were, as a rule, present during these conversations, and at times played a central role in grasping the families' view. The family was in some cases familiar with the patient's attitude, though not always, and having to make a decision on behalf of the patient was sometimes difficult. When the nurses registered doubt or a need for additional information, they collaborated with the physicians and offered the family the information they needed. No care providers wished to influence the family's decision, but wanted a decision in accordance with the patient's or family's wishes. As one physician said: "We have to make sure that the donation is in accordance with the patient's or at least the families' wishes. This is a difficult balance, but we have to try." Respect for the family's decision was emphasized by all health professionals.

#### *Partly present while waiting for death*

In general, several hours passed after the subject of organ donation was introduced until the patient's condition progressed to brain death. Treatment was continued during this period. Interaction with families may be characterized as partly present, and the providers focused on easing the family's wait for death and arranging for a farewell. The overall meaning was the respect for the families' decision.

At this stage there was no hope of recovery. The atmosphere in situation was changed, and the nurses prepared the family for spending time with the dying patient and let them visit as much as they wanted. Whenever possible they moved the patient to a single room, but most often the patient remained in the open ICU as no single rooms were available. The physicians followed up the family with information about further procedures and were available to answer questions. During this phase, nurses and physicians alike were more sensitive and reserved in their interaction with the family. They were supportive, but also emphasized giving the family space and

privacy in their grief. One nurse said “it was not much to say, only being there for them, being available.” Although the professionals’ main focus was on the family, they could not exclude the dying patient from their attention, but had to continue the care until the patient was transferred for donation or treatment was withdrawn.

Arrangements for a farewell were adjusted to the family’s needs. As most such farewells were made in the open ICU, the family was accorded some privacy and protection from the activity in ICU. This was not an ideal situation, but they tried to make the best of it. Arranging for a farewell with a donor patient was, however, different from arranging for a farewell with other dying patients:

“...We are familiar with critically ill and dying patients, but not with these situations. A donor patient is in need of optimal treatment, even if he is dying. You also have a family in crisis. A lot of practical tasks and emotional challenges must be met, and you have to constantly change between the two ... In other situations there’s another mode, and when the patient becomes unstable, you don’t intervene but take care of the family. But in these cases, you have to keep optimizing medication and keep thinking more of the donor patient than the family...” (Nurse)

The transition from life to death is not as clear in cases of brain death, and the family must make their farewells with, in many ways, a still “living body.” Some physicians acknowledged the challenge this presented, and prepared the family for these aspects when informing them about the donation process. They also offered the family a chance to return after the donation, but this was usually refused. For those who did want to return, the nurses prepared for a

dignified farewell, as they did for the family in the referred example. When the hospital chaplain was involved and the family so wished, a simple but solemn ceremony with the family present at the bedside was arranged. In other cases there was no ceremony, but the family was given the opportunity of a farewell. When the family refused organ donation, the physicians asked if they wanted to be present when the ventilator was turned off. This was then done without disturbing alarms or signals from technical equipment. The family was subsequently able to grieve by their loved one’s bedside.

As the families were unprepared for these unexpected and tragic events, the nurses presented the families with written information on how to deal with the death of a loved one. They also offered follow-up conversations by phone, 4 to 6 weeks later. The families generally accepted the offer of such conversations. The dual interaction process is visualized in Figure 1.

**Discussion**

Findings show that the themes in health professionals’ experience of interaction with families appeared as different phases in a dual process that changed over time. During the process the professionals attended to patients as well as to their families; the interaction depended, however, on the patients’ condition. Hence, the priority of the professionals’ attention varied. In the beginning of the process the patient was the main focus and toward the end, the family. This variation seems not to be a choice—but an imperative based on the participants’ caring priorities, which may be illuminated by a phenomenological perspective on concern.

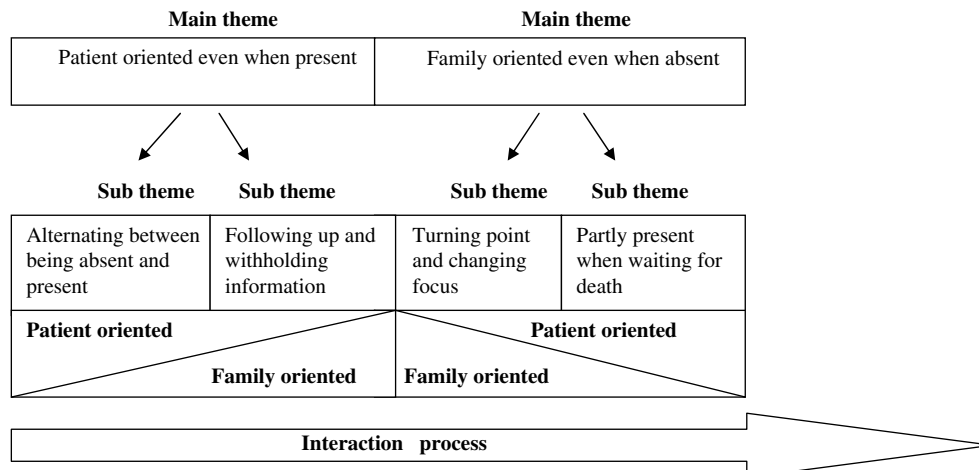


Figure 1. The dual interaction process.

Concern in a phenomenological perspective expresses interest for others as well as for oneself, the former being the subject of this discussion. Heidegger (1962) uses the concept of concern to describe how persons are involved in the world. He says that we involve ourselves in the world because things or people matter to us and calls this way of being involved “concern” (“besorgen”). Concern is a form of directed attention and engagement that changes over time and situations, and designates possible ways of being-in-the-world. It is the existential sense of being involved and describes the meaning for the person. As human beings are connected to the world by care, concern is visible as care (“sorge”) and describes a wide range of involvement (Benner & Wrubel, 1989; Heidegger, 1962): in the current context from performing technical procedures to conversing about existential matters. This means that concern distinguishes care from non-care and that care may have many “faces” depending on the situation. One important distinction in the meaning of care is the difference between “leaps in” (“einspringen”) and “leaps ahead” (“vorausspringen”) (Benner & Wrubel, 1989, pp. 48–49; Heidegger, 1962, pp. 158). To “leap in” means that one must take over the care for the other because the other is thrown out of his usual position, whereas to “leap ahead” is to empower the other to do what he wants to do or to be what he wants to be (Benner & Wrubel, 1989, pp. 48–49; Heidegger, 1962, pp. 158–159). During the two first phases the providers had no other choice than “leaping in” or taking over the care for the severely brain-injured patient whose life was threatened by a swelling of the brain. Nevertheless, caring for patients includes caring for families, and in that way the professionals and the families had common concerns and goals. Despite this common interest, the focus on the patients moves the families into the background. The period of clarification of prognosis was a troubled time for the families. The threat of losing a loved one is described in other studies as one of the most stressful situations for a family, and the significance of understandable information is emphasized (Frid, 2002; Gill & Hulatt, 2000; Jacoby, Breitkopf & Peace, 2005; Orøy, 2002; Pelletier, 1992, 1993). Despite understandable information, if the family is seen as an extension of the patients, it is easy to overlook the individual needs of the family. In a way, the professionals are absent also when they are present.

When the professionals realized that they were unable to save the patient’s life, a turning point occurred in the interaction with the family, and the main concern shifted from patient to family. From

being in background during the initial phases, the family gradually became more visible until its members became the main focus of the professionals’ attention in the last phases. Whereas concern in the first phases was characterized by “leaping in” or “taking over” the care for the patient, concern in the latter phases may be characterized as “leaping ahead” or empowering the families (Benner & Wrubel, 1989, pp. 48–49; Heidegger, 1962, pp. 158–159). When there was no hope for recovery, they “brought the care back” to the families by involving them in conversations and decisions about what to do. Organ donation was presented as an option, and the families were given time to consider the patient’s wishes. In spite of a high level of competence and expertise, the timing of the question was a challenge, which is in line with other studies (Pellereiaux et al., 2008; Pont Castellana et al., 2008; Sanner, 2007; Sadala, Lorencon, Cercal & Schelp, 2006; Kent, 2002, 2004). According to Williams et al. (2003), discussing severe brain injury, brain death, and organ donation with families is a specialized form of end-of-life decision making and care in ICU, and the presence of the knowledge, skills, and attitudes needed for physicians and nurses to promote this decision making varies. Despite high levels of competence and expertise, the professionals had varying training in discussing organ donation and following up families in such situations. They were, however, aware of the sensitive nature of these situations and the meaning of being sensitively present and of respecting the families’ decisions.

The focus of the professionals’ concern changed during the different phases of the interaction process. This may illustrate the temporal aspect of concern. The interaction process also illustrates different areas of concern: concern for the patient, for the family, and for the donation process. Within each area there are different expressions of caring, illustrating different ways of being involved in interaction with the families. Variations appeared between the different professions but also within the professions. While the physicians went in and out of the situation, were responsible for formal information, and for presenting and discussing the option of organ donation with the families, the nurses were mainly by the bedside, and along with caring for the critically ill patient or potential donor, they also followed up the families with information and emotional support. The hospital chaplains were not routinely involved, but had a family and existential orientation when they were. According to Benner and Wrubel (1989), involvement can be understood only in relation to particular situations. The manner in which persons approach their particular concern and the way they involve



themselves in situations, represent central issues from a phenomenological point of view. Benner uses Heidegger's terms "ready-to-hand" and "unready-to-hand" to describe a person's level of involvement. "When the person is actively involved in the situation, the equipment is ready-to-hand; it is unnoticed and taken for granted. If the equipment breaks down, it is noticed and unready-to-hand and the person lose the grasp that was available at ready-to-hand" (Benner & Wrubel, 1989, p. 81; Heidegger, 1962, pp. 102–103). Although Heidegger used the concepts "ready-to-hand" and "unready-to-hand" in relation to equipment, it is also possible to use the concepts in relation to the professionals' conversations with the families. For example, the professionals' conversations were described as manageable until they needed to present the subject of organ donation to the family. When this happened, the situation changed and the talking became increasingly difficult because the situation was sensitive and the professionals were afraid of causing any harm. Or, they were "ready-to-hand" when the conversation was flowing, and became "unready-to-hand" when the conversation halted or they could not reach the family. Nevertheless, the situation indicates that the life-sustaining treatment is no longer the major challenge, but rather the interaction with the family. This is on the professionals' mind also when not present.

The dual focus accompanied the professionals' interaction with the families throughout the process. During the first phases the professionals were concerned with the patient as well as the family, and although the main focus was on the family in the last phases, their attention was still divided because their concern was directed toward the donation process and toward potential patients in need of organs. Although treatment of the patient present was no longer a goal in itself but a means to helping others, they did not exclude the patient from their attention. In cases when the family refused organ donation, the professionals continued to care for the patient until the treatment was withdrawn or until the patient returned from surgery in cases where the families consented to donation.

### **Strengths and limitations**

The strength of this study is that the findings are based on a combination of participant observation and in-depth interviews. Through the methods chosen, the researcher came close to the context, the situation, and the health professionals' experiences. This also offered the opportunity to obtain knowledge through first-hand experience that could

not have been obtained from an interview alone. While the interview gave insight into the participants' experiences, the observations contextualized the interviews and put them into perspective. In order to recognize a meaningful pattern, the interactions interpreted are simplified for analytical purposes. However, the insight gained is transferable to interactions with families in similar situations and also to interaction with families in ICU in general. The study is limited by the fact that the researcher did not follow the process from the beginning, but became involved only after the patients and the families were admitted to ICU. All the health professionals involved in each situation were not interviewed. The participants were interviewed once. The principles of openness, sensitivity, and critical reflection are central to phenomenological research. Hence, strengths and limitations also arise associated with the researcher's background. The researcher's contextual experience and knowledge represent strengths, whereas the influence of those pre-understandings on the observations represents a potential limitation.

### **Conclusion and implications for practice**

This paper focuses on health professionals' experiences with interaction with families during life-threatening illness or trauma and organ donation. Findings show the professionals' efforts at doing their best to save lives, recognize death, and address the possibility of having the dying patient donate his or her organs. Interaction with the families was dominated by patient orientation early in the process and family orientation toward the end of the process. While being occupied with saving a patient's life, the provider's concern must be the patient. There is no alternative. This may cause the professionals to be "absent" even when they are present. Later, when they have the opportunity to focus more on the family, they struggle to find the right way of being present for the family. The situation is turned upside down—and they become "present" even when they are absent. Variations appeared with regard to the extent to which the various groups were patient or family oriented. This is related to the area of their professional roles and functions in the situations. Our main impression is that the interaction with families was dominated by care, although the professionals concern was shifting. However, it is important to allow for that the professionals cannot be family oriented all along. Because of the complexity of caring for both patients and families, the situations demand resources' to relieve the nurses in particular in the most demanding situations. This will increase

the quality of the interaction with families through the different phases, and is especially important when the nurses are untrained or have less or no experience from similar situations.

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