The circle of strength and power
Experiences of empowerment in intensive care

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To Erling, Simon and Linus, for empowering my life!

Patients and their next of kin are not guests in our organisation
- We are guests in their lives!
Freely quoted from Don Berwick
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Patient experiences compared to next of kin and staff beliefs (IV) ....... 25
Patients and next of kin in intensive care often experience powerlessness, anxiety and distress and intensive care staff are repeatedly exposed to traumatic situations and demanding events. Empowerment has been described as a process of overcoming a sense of powerlessness and a model through which people may develop a sense of inner strength through connections with others. The aim of this thesis was to describe empowerment as experienced by patients, next of kin and staff in intensive care and to compare patient’s experiences with staff and next of kin beliefs. Empowerment is reflected in this thesis as experiences of inner strength and power and of participation/self-determination.

The study was based on open-ended interviews with 11 patients, 12 next of kin and 12 staff members from two intensive care units in southern Sweden. A phenomenological perspective was applied in three studies, while a qualitative content analysis was used in the forth study.

Findings showed that nourishing relationships were of crucial importance, and contributed to every participant’s experiences of empowerment regardless of whether he/she was an intensive care patient, a next of kin or a staff member. Patients were found to be strengthened and empowered by a positive environment where their own inherent joy of life and will to fight was stimulated, where they felt safe and a sense of value and motivation were encouraged, where they received additional care and were taken seriously and listened to. Next of kin were extremely important to patients’ experiences of safety, value, human warmth and motivation, and patients were strengthened when their next of kin were acknowledge and welcomed by others.

Next of kin in intensive care were strengthened and empowered by a caring atmosphere in which they received continuous, straightforward and honest information that left room for some hope and in which closeness to the patient was facilitated and medical care was experienced as the best possible. Some informants were also empowered by family support and/or participation in caring for the patient. Intensive care staff were empowered by both internal processes such as feelings of doing good, increased self-esteem/self-confidence and increased knowledge and skills, and by external processes such as
nourishing meetings, excitement and challenge, well functioning teamwork and good atmosphere.

When comparing patient experiences with staff and next of kin beliefs, there was agreement regarding joy of life and will to fight being essential to patients’ experiences of inner strength and power, but staff and next of kin seemed to see this as a more constant individual viewpoint or characteristic than the patient did. Next of kin, and especially staff, seemed to regard the patient as more unconscious and unable to participate in the communication and interaction process than the patient him/herself experienced. A mutual and friendly relationship was experienced by the patients as highly empowering, while a more professional relationship was emphasized by the staff.

These findings could serve as a basis for reflection about patient, next of kin and staff experiences of strength and power and if empowerment is seen as a dimension in quality of care, the findings from this thesis ought to be taken into consideration to increase the quality of care in intensive care.
LIST OF PAPERS

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


IV  Wählin I, Ek A-C, Idvall E. Empowerment in intensive care: Patient experiences compared to next of kin and staff beliefs (submitted).
INTRODUCTION

It is known that intensive care patients often experience powerlessness, lack of knowledge/information, vulnerability, defencelessness, anxiety and distress (Hafsteindóttir 1996, McKinley et al. 2002, Russell 1999). It is also known that next of kin play an important role in the intensive care patient’s experiences of comfort, security, relaxation and reassurance (McKinley et al. 2002), but as admission to an intensive care unit is recognized as an extremely stressful event for a patient’s next of kin as well, they could have difficulty supporting the patient (Leske 1998). It is hence valuable to learn more about how ICU patients and their next of kin can be strengthened and empowered.

Intensive care staff are repeatedly exposed to traumatic situations and demanding events, and burnout symptoms have been found to be frequent among critical care nurses and physicians. A higher level of psychological empowerment is associated with fewer burnout symptoms and increased work satisfaction, and if ICU staff are to be able to take part in an empowerment process, they themselves probably need to feel strengthened and empowered in their professional role (Chanvasse 1992).

Because intensive care patients often have difficulties communicating staff and next of kin have to interpret their wishes, but there is limited knowledge about how proper a picture next of kin and staff have of the intensive care patient’s experiences of strength and power and of participation/self-determination.

In this thesis, empowerment is reflected as experiences of inner strength and power, and of participation/self-determination.
BACKGROUND

Intensive care

The intensive care unit (ICU) serves a vital function in the care of critically ill individuals. According to the Swedish Society of Anaesthesiology and Intensive Care (SFAI 2008), intensive care means to prevent and treat failure in one or several organ systems, so that continual life can be meaningful from the patient’s point of view. Intensive care involves surveillance, diagnostics, treatment, and care of patients with acute (life-threatening) illness, and often has to be performed round the clock. According to the Swedish Intensive Care Registry (SIR 2008), there are 86 intensive care units in Sweden; just over half of these units submitted statistics to SIR in 2007. The annual report for 2007 showed that the most frequent diagnoses for admission to ICU were sepsis, gastrointestinal bleeding, multiple trauma, cardiac arrest, chronic obstructive pulmonary disease and pancreatitis. The mean length of stay at ICU was about three days, with great variation. About 93% of the patients survived the ICU period, and three months after admission, 80% of patients were still alive. Most ICUs in Sweden are so-called general ICUs, where critically ill patients with a wide range of diagnoses are cared for on the same unit, but there are also some ICUs that specialize in thorax disease, neurological disease, burn injury or paediatric care. Regardless of its character, intensive care is often associated with severe illness, advanced technology and abrupt changes, which greatly affect patients, next of kin and staff in various ways.

Patient

Critically ill patients often experience powerlessness, lack of knowledge/information, vulnerability, defencelessness, anxiety and distress (Hafsteindóttir 1996, McKinley et al. 2002, Russell 1999). Sleeping problems, thirst, pain, discomfort and difficulty communicating have also been reported in a number of studies (Stein-Parbury & McKinley 2000). Between 20% and 80% of ICU patients suffer from delirium, i.e. a disturbance of consciousn
Background

and cognition that develops over a short period and fluctuates over time. Differences in frequency are recognized to be related to the severity of illness and the diagnostic method (Girard et al. 2008). Although medical treatment often focuses on trying to reduce ICU delirium (Girard et al. 2008), caring relationships with relatives and staff, trust, confidence and a feeling of self-control have also been found to decrease ICU patients’ fear and could be helpful in preventing the occurrence and/or duration and intensity of unreal experiences (Granberg et al. 1999).

Critical illness and intensive care may have implications for patients’ psychological wellbeing, not only in the ICU but also after discharge (Geary 1994). The goal of intensive care is not only to save lives but also to support patients and their relatives during critical illness (Pattison 2005). Hofhuis et al. (2008) found that almost one-fourth of ICU patients reported having psychological problems after hospital discharge. Fear was most common, but concentration disturbance, hallucinations, depression and forgetfulness were also mentioned. About 13-27% of ICU patients may develop Post-Traumatic Stress Disorder (PTSD) as a result of treatment in the ICU (Rattray and Hull 2008). The number of adverse experiences such as anxiety, respiratory distress, pain and nightmares while at ICU increase the risk of PTSD, which in turn is associated with major impairments in health-related quality of life (Schelling et al. 2008).

It has been shown that the attitude of staff and how the patient is treated at the ICU has great importance to their wellbeing and recovery (Granberg et al. 1998, Hofhuis et al. 2008), and there is a need to focus more on developing and evaluating appropriate interventions to improve psychological outcomes for ICU patients (Rattray and Hull 2008).

Next of kin

Admission to an ICU is recognized as an extremely stressful event, not only for the patient but also for his/her next of kin, who often face a completely unexpected and difficult situation, causing experiences of shock, fear, guilt and worry (Hughes et al. 2005, McKinley et al. 2002, Paparrigopoulos 2006). However, next of kin play an important role in the intensive care patient’s experiences of comfort, security, relaxation and reassurance by simply being present and by providing information and a link to reality (McKinley et al.
Background

In a study by Bergbom and Askwall (2000), patients expressed feelings of an inner calm when their next of kin were with them. Even when they were asleep, they could feel the presence of their next of kin, and no matter how good and kind a staff member was, this was not the same as the very special contact they had with their next of kin. Calm and well informed next of kin are a valuable resource not only to the patient, but to the caring staff as well (Williams 2005). With a high level of stress, however, it could be difficult to support the patient (Leske 1998). Ågård and Harder (2007) found that next of kin often felt insecure regarding their role at the ICU. Finding a place and adapting to life at the ICU required a great deal of energy, and they highly appreciated being invited to stay by the patient’s bed and being instructed on how to participate in the patient’s care or comfort him/her.

In the acute phase, next of kin prioritize the welfare of their ill family member and are often not even aware of their own needs (Verhaeghe et al. 2005). In order to be able to support the patient, next of kin often suppress their own anxiety, sorrow and needs, and try to endure the situation in an emotionless way instead of suffering emotionally (Ågård and Harder 2007). It has been shown that the needs of next of kin are underestimated by caring staff, and as next of kin often have difficulty asking for help, the initiative for meeting their needs has to be taken by the caring staff. Most research on family needs has been conducted using one and the same instrument, the Critical Care Family Needs Inventory (CCFNI), developed by Molter (1979). When reviewing scientific knowledge about the needs and experiences of family members of intensive care patients, Verhaeghe et al. (2005) concluded that more qualitative studies needed to be conducted so that their experiences and the process they go through could be better understood and items that may have been missed in instruments could be identified. This would increase the opportunity to optimize the care for ICU patients’ next of kin and, as a consequence, also the care for ICU patients.

Staff

Intensive care staff are often confronted with death and tragedy, which, together with the intense nature and pace of their work, cause stress. Stress contributes to turnover (Cartledge 2001) as well as burnout syndrome, which
has been found to be common both among ICU nurses (Poncet et al. 2007) and physicians (Shehabi et al. 2008). Organizational factors such as tight schedules and heavy workload, along with perceived conflicts with patients, families or other staff members, are also associated with an increased risk of burnout symptoms, while good relations and teamwork are associated with a decreased risk of burnout (Embriaco et al. 2007). Staff burnout, characterized by negative attitudes, emotions and behaviours towards one’s work (Maslach 2001), appears to have serious consequences for both the individual caregiver’s wellbeing (Embriaco et al. 2007) and the quality of care (Garman et al. 2002, Shirom et al. 2006). Intensive care nurses have shown an increased prevalence of PTSD, generating sleep problems with nightmares and muscle tension, and being irritable, agitated annoyed or angry (Mealer et al. 2006).

A higher sense of psychological empowerment in the workplace has been found to be associated with decreased job stress (Bartram et al. 2004), lower levels of general mental ill health, fewer burnout symptoms and decreased numbers of sick-leave days (Hochwälder and Bergsten Brucefors 2005 b). Empowerment is also related to commitment and trust in management, and to work satisfaction (Kuokkanen and Katajisto 2003) and efficacy (Spreitzer 1997, Laschinger et al. 2001).

**Interactions**

Intensive care patients comprise an extremely vulnerable patient group who depend on technology and staff to not only maintain and sustain their lives, but also manage their intimate body care (Wang et al. 2008). Intensive care patients often have difficulty expressing their needs and wishes, which generates a need for other people, preferably ICU staff and next of kin, to interpret their wishes. If caring staff cannot perceive a patient’s need, they cannot meet it and are thus not able to provide the care the patient requires (Cornock 1998). As next of kin know the intensive care patient and his/her history, they might have the opportunity to understand the patient and to translate, explain and interpret information between the patient and the caring staff (McAdam et al. 2008).

If next of kin and staff try to empower the ICU patient, this is probably performed in accordance with their beliefs concerning what the patient
Experiences as empowering. ICU nurses have previously been found to have difficulty estimating ICU patients’ perceptions of environmental stressors (Cormack 1998), and inaccuracies have been found when comparing ICU patients’ and nurses’ ratings of quantity and quality of sleep. However, few studies have been found that include a comparison between ICU patients’ experiences and staff beliefs, and no comparison has been found between the ICU patient’s experiences and his/her next of kin’s beliefs. It is therefore valuable to gain more knowledge about how well next of kin and staff beliefs correspond to patients’ own experiences.

Empowerment

The concept of empowerment has been widely used, e.g. in social theory, where unprivileged groups are described as oppressed (Ward and Mullender 1991), in organizational and management theories (Kanter 1979), and in social psychological theory (Kuokkanen and Leino-Kilpi 2000). There is, however, no unambiguous definition, and empowerment has been seen as both a process and a result (Gibson 1991). Rappaport (1984) regarded empowerment as easy to define in its absence – powerlessness, helplessness, alienation, loss of sense of control – but more difficult to define positively because it takes on different forms in different people and contexts.

Characteristics

As the definition and meaning of empowerment are quite different from one investigation to another, an attempt has been made here to elucidate common characteristics of the concept when used in medicine and care, and from the perspective of patients, next of kin and staff. In this area, empowerment has been used in accordance with, e.g., cancer patients (Bulsara et al. 2004, Mok 2001), chronic disease (Anjoulat et al. 2007, Tsay and Hung 2003), diabetes patients (Adolfsson et al. 2004, Florian and Elad 1998), orthopaedic patients (Loft et al. 2003), mental health care (Ellis-Stoll and Popkess-Vawter 1998, Fingeld 2004, Rogers et al. 1997, Scott et al. 1999) and care for elderly patients (Faulkner 2001, Tu et al. 2006). Empowerment has also been examined in relation to next of kin (Man et al. 2003, Mok et al. 2002) and staff (Hochwälder...

In these studies, five common characteristics were discerned: a mutual and supportive relationship, knowledge, skills, power within oneself and self-determination. These five characteristics are described below.

**A mutual and supportive relationship**

A prerequisite for an empowerment process is that two or more individuals are actively involved. Their relationship is built on equality, which means that everyone’s experiences, feelings, etc. are important and of equal value (Fingeld 2004). Engagement, acknowledgement, mutual respect, and active listening are essential components (Ellis-Stoll and Popkess-Vawter 1998, Mok et al. 2002). Possibility and support in expressing feelings, exploring problems and developing solutions are facilitated within a positive and caring atmosphere (Adolfsson et al. 2004, Tsay and Hung 2003). An empowering relationship can give people a feeling that they are not alone, that someone is walking the difficult path with them (Mok et al. 2002). In an empowerment process, individuals themselves select their learning needs and identify problems, strengths and barriers to making behavioural changes and setting goals, as well as establish a plan to reach these goals (Tsay and Hung 2003).

**Knowledge**

In this context, knowledge is not an objective appraisal, but rather a person’s individual perceptions of their own knowledge in relation to the situation they have to handle. Information thus has to be personalized and adapted to the individual’s own needs. A mutual exchange of information is a cornerstone in the empowerment process. Although professionals, leaders, teachers, etc., may bring professional knowledge, all parties have unique perceptions and knowledge and everyone is placed in a position to learn from each other (Loft et al. 2003, Man et al. 2003, Rogers et al. 1997).
**Skills**

Skills are developed through training and reflection, and contribute to a belief in one’s own ability to sufficiently handle a situation or have an influence on events (Man et al. 2003, Rogers et al. 1997). Enhanced critical thinking and positive feedback are helpful in skill development. Skills needing development can be of very different character, for instance handling a specific task, mastering ways to improve time management and planning for work, or handling personal frustrations (Itzhaky et al. 2003, Rogers et al. 1997 Tsay and Hung 2003).

**Power within oneself**

Empowerment involves experiences of increased energy (Bulsara et al. 2004, Mok 2001). An important principle is that it is not possible to empower another person, without an active involvement from the person him/herself. In an empowerment process, power is not given by someone to someone else, but is instead created *within* someone. Experiences of emotional strength and power are created and catalysed in an empowering interaction. Power within oneself can also be described as fighting spirit or self-efficacy/self-esteem (Anjoulat et al. 2007, Bulsara et al. 2004)

**Self-determination**

Self-determination is enabled through the possibility to participate and make one’s own decisions (Thomas and Vellhouse 1990), weigh advantages versus disadvantages, negotiate and make choices. The principle of self-determination means to acknowledge that only a person him/herself can identify which areas of his/her life are most in need of change and how much different options are linked to meaningful outcomes for him/her (Adolfsson et al. 2004).
Quality of care

The concern for quality of care is well established among health care professionals and policy-makers. Quality of care is a complex concept that has to be looked at within a wide scope (van Driel et al. 2005). Donabedian (1980) identified the three main components of quality of care as structure, process and outcome. Structure refers to the relatively stable characteristics of the care providers, the tools and resources they have at their disposal, and the physical and organizational settings in which they work. Structure includes human, physical and financial resources, while process is the interactions and activities that occur within and between caring staff and patients. Outcome refers to a change in the patient’s current and future health that can be related to previous health care (Donabedian 1980). Structural and process quality are preconditions for outcome quality (Velasco-Garrido et al. n.d.). When procedures used in specific situations are clearly associated with good results, the presence or absence of these procedures could be accepted as evidence of good or bad quality (Donabedian 1980). Patient, next of kin and staff empowerment can be seen as important factors that can be assumed to contribute to increased quality of care by influencing the interactions and activities within and between patients, next of kin and ICU staff. For this reason, it is valuable to learn more about patient, next of kin and staff empowerment in intensive care.
Aims of the thesis

AIMS OF THE THESIS

General aim:

The overall aim was to describe empowerment as experienced by individuals in intensive care.

Specific aims:

To describe patient empowerment in an intensive care situation. (I)

To describe next of kin empowerment in an intensive care situation. (II)

To describe empowerment from the perspective of intensive care staff; What makes intensive care staff experience inner strength and power? (III)

To compare patient experiences of empowerment with next of kin and staff beliefs. (IV)
Design

A qualitative approach was chosen for this thesis. Qualitative research is rooted in a naturalistic philosophy, which asserts that reality is subjective rather than objective, because there is not a single reality but rather multiple realities (Polit and Hungler 1999). Qualitative approaches are intended to generate knowledge grounded in human experiences (Sandelowski 2004) and bring the perspective of the people it concerns (Grypdonck 2006).

As a phenomenological method is aimed to reveal how we experience the world in which we live (Rapport and Wainwright 2006) and to examine a phenomenon from the view of human experiences (Karlsson 1995), this was found to be an appropriate method in describing patient, next of kin and staff experiences of empowerment (I-III). Phenomenological analysis is based on presences or experiences, not in their objective sense but in the meaning the phenomenon has for the subjects experiencing it (Giorgi 1997). In order to recognize the phenomenon as it shows itself, pre-assumptions and theories have to be set aside (bracketing) so that the phenomenon can be meet in as free and unprejudiced a manner as possible (McNamara 2005). A pre-theoretical lived understanding is, however, a prerequisite for being able to perform a specific investigation and, according to Karlsson (1995), an understanding of the phenomenon takes its form in the tension between the researcher’s pre-understanding and strive to be as open as possible. In this thesis, the author’s lived understanding as an intensive care nurse was seen as a resource for understanding the meaning in what participants discussed. However, an attempt was made to put all theories and pre-assumptions aside and adapt an open attitude through what was narrated in the interviews.

Comparing someone’s (e.g., a patient) lived experiences with someone else’s (e.g., next of kin or staff) beliefs about their experience involves a comparison between two different types of data. The first type is direct experiences whereas the second is people’s ideas or opinions about something.
Method

Phenomenological analyses presuppose direct experiences of a phenomenon (Patton 2002) and consequently cannot be used to analyse someone’s beliefs. As content analysis provides a scientific method for analysing different kinds of data collected using a variety of qualitative research approaches, and emphasizes differences between and similarities within codes and categories (Graneheim and Lundman 2004, Hsieh and Shannon 2005, Kondracki et al. 2002), this was found to be an appropriate method for comparing patient experiences with staff and next of kin beliefs regarding their experiences (IV). The analysis could focus on either what the text says, i.e. what is visible at the surface level (manifest content), or what the text talks about, i.e. its deeper meaning (latent content), or both (Graneheim and Lundman 2004, Kondracki et al. 2002). According to Graneheim and Lundman (2004), a text analysis always involves multiple meanings and there is always some degree of interpretation in approaching a text, but interpretation varies in depth and abstraction between manifest and latent content analyses. Both a manifest and a latent qualitative content analysis were used for comparing patient experiences with staff and next of kin beliefs regarding their experiences (IV).

Participants and procedure

Patients, next of kin and staff members were selected in collaboration with nurses working at one small-sized and one medium-sized general ICU in southern Sweden. Participants with various experiences were sought, in order to increase the possibility to shed light on the research question from a variety of aspects (Patton 2002).

Patients (I)

Open-ended interviews were conducted with 11 patients with different diagnoses, days in ICU, ages and genders. Patients were aged 28-83 years and had been cared for for 3-41 days in ICU. Most patients suffered from acute illness, but two had been admitted for planned major surgery. Interviews were conducted in a quiet room at the hospital, at the patient’s home or at another place in accordance with the patient’s wishes, between 4 and 30 days after discharge from ICU. The time lapse between discharge and interview
Method

depended on the participant’s condition, preferences and practical reasons. The interviews were initiated with an open-ended question in which the patients were asked to narrate, in as much detail as possible, their experiences from their time in ICU. Follow-up questions were posed about experiences of strength, power and participation. Each interview lasted between 30 and 80 minutes.

Next of kin (II)

Open-ended interviews were conducted with 12 next of kin aged 35-75 years. They were spouses, children, parents or siblings of patients cared for in ICU for 8-21 days. Interviews took place in a quiet room at the hospital or at the participant’s home or workplace, between 1 and 60 days after the patient had been discharged from ICU. Differences in when the interviews took place depended on when the participant had time and felt strong enough to participate in an interview. During the interview, informants were asked to narrate their experiences from the ICU period in as much detail as possible. Follow-up questions were posed about experiences of strength, power and participation. The next of kin were also asked about what they believed increased the patients’ experiences of strength and power while being cared for in ICU and about their experiences of patient participation. Each interview lasted 30-65 minutes. Patients in Study I and next of kin in Study II had no connection to each other except that they had experiences of care at the same ICUs.

Staff (III)

Open-ended interviews were conducted with four registered nurses, four enrolled nurses and four physicians aged 27-56 years. Five participants were men and seven were women. They had worked in ICU 5-35 years. The interviews took place in an undisturbed room at the ICU or at another place at the hospital, in accordance with the participants’ wishes. Staff were asked to narrate a situation they had experienced as especially good or bad, or a day when they felt satisfied when leaving work. They were also asked what they believed increased a patient’s experiences of strength and power when being
Method

cared for in ICU and about their experiences of patient participation. Follow-up questions were posed about situations, thoughts and feelings. Interviews lasted between 20 and 65 minutes.

**Patient experiences compared to next of kin and staff beliefs (IV)**

In Study IV, patient interviews were reanalysed and compared with parts of next of kin and staff interviews consisting of information about their beliefs regarding patients’ experiences of strength, power and participation. Parts of interviews that were analysed and used in this study are illustrated in Figure 1. In Study I, patient interviews were analysed using a phenomenological method, but in Study IV were reanalysed using content analysis, as it was found to be difficult to compare data generated from different analysis methods. The first part of the interviews with the next of kin was analysed in Study II and the first part of the staff interviews was analysed in Study III.

![Figure 1: The grey parts of interviews were analysed and compared in Study IV.](image-url)

| 11 patients | Interviews about patients’ experiences of empowerment |
| 12 next of kin | Interviews about next of kin’s experiences of empowerment |
| 12 staff | Interviews about staff’s experiences of empowerment |
| | Interviews about next of kin’s beliefs regarding patient empowerment |
| | Interviews about staff’s beliefs regarding patient empowerment |
Data analysis

Patient, next of kin and staff experiences (Papers I-III)

All interviews were audio taped and transcribed verbatim. Data analyses were conducted in accordance with an empirical phenomenological psychological (EPP) method developed by Karlsson (1995). First, interviews were read until a good grasp of the whole had been obtained. The text was then divided into smaller meaning units (MUs), reflecting different meanings in the text, according to the aim of the study. A new MU started when a shift in meaning was discerned. Each MU was then concluded and transcribed from the participant’s concrete expression into a new more common text based on the researcher’s nursing perspective. After this transformation, meaning units were synthesized into one specific description of the phenomenon for each interview. Lastly, all specific descriptions in each study were compared and synthesized into one description corresponding to the aim of the respective study. Analysis resulted in both general structures (characteristics), running through all interviews, and typological structures, found in some but not all interviews. Findings in each study were complemented with an essential structure, reflecting all general and typological structures in respective study.

Patient experiences compared to next of kin and staff beliefs (IV)

The units of analysis (Graneheim and Lundman 2004) in this study were patient interviews and parts of next of kin and staff interviews consisting of information about their beliefs regarding patients’ experiences of strength, power and participation (Figure 1). Patient experiences, next of kin beliefs and staff beliefs were assembled into separate texts, one for each group. In the first phase, texts were analysed separately in accordance with a qualitative content analysis method (Graneheim and Lundman 2004). All interviews were first read through to obtain a sense of the whole. Texts were then divided into smaller meaning units (MUs), which were condensed and sorted into subcategories and categories. The underlying meaning of each text (one for
Method

patients, one for next of kin and one for staff) was expressed in a theme. The analysis process involved continuous movement between the whole and the parts of the text. Examples of MUs, condensed MUs and subcategories from the category “Joy of life and will to fight”, are presented in Table 1. The exemplified category is labelled as such even if some of its MUs only describe one of the parts (joy of life or will to fight), because these two components are intertwined in most cases. In a final step, themes, categories and subcategories in patient, next of kin and staff interviews were compared and similarities and differences were sought. The first part of the analysis can be seen as a manifest content analysis while the latter steps, including creating themes and comparing similarities and differences, can be seen as a latent analysis (cf. Graneheim and Lundman 2004).
<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Subcategory</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>He has always been optimistic and strong as a person</td>
<td>Optimistic and strong as a person</td>
<td>Joy of life and will to fight</td>
</tr>
<tr>
<td>Next of kin</td>
<td>Pepped to not give up</td>
<td>Pepped to not give up</td>
<td>Joy of life and will to fight</td>
</tr>
<tr>
<td>Staff</td>
<td>Praised and stimulated</td>
<td>Praised and stimulated</td>
<td>Joy of life and will to fight</td>
</tr>
</tbody>
</table>

### Joy of life and will to fight from the perspectives of patients, next of kin and staff

<table>
<thead>
<tr>
<th>Patient</th>
<th>Next of kin</th>
<th>Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have always been glad and positive, and strong too, and I have a high pain threshold.</td>
<td>You should get healthy again, as my son said.</td>
<td>If you only know that it will be better, this is help.</td>
</tr>
<tr>
<td>My mood improved, and that is always positive and good, if you can be in a good mood.</td>
<td>That made me... no I can't give up.</td>
<td>If only know that it will be better, this is help.</td>
</tr>
<tr>
<td>I experienced that both my [dead] father and mother were there behind a door and I thought there were there to help me get going // and it helped.</td>
<td>If you only know that it will be better, this is help.</td>
<td>If only know that it will be better, this is help.</td>
</tr>
<tr>
<td>If you only know that it will be better, this is help.</td>
<td>If you only know that it will be better, this is help.</td>
<td>If only know that it will be better, this is help.</td>
</tr>
<tr>
<td>There is something, a fighter in us all, more or less. Something you bring with you. To not give up, even when you are in a situation like this, to still have the energy to... fight.</td>
<td>There is something in us all, more or less. Something you bring with you. To not give up, even when you are in a situation like this, to still have the energy to... fight.</td>
<td>There is something in us all, more or less. Something you bring with you. To not give up, even when you are in a situation like this, to still have the energy to... fight.</td>
</tr>
</tbody>
</table>

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**Method**

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Method

Ethics

All participants received verbal and written information before deciding whether to participate. They were able to choose time and place for their interview, and were informed about their ability to discontinue participation whenever they wanted, without giving a reason. Talking about experiences from intensive care can evoke violent emotions, but previous experiences show that this can also be experienced as relieving. As interviews started with an open question in which participants were asked to narrate their lived experiences, they had an opportunity to choose what they did or did not want to tell. Patients and next of kin can experience themselves as dependent on caring staff, and for this reason have difficulties expressing negative experiences and emotions regarding care. However, the interviews were not carried out until after they left the ICU, the researcher performing interviews did not work in the departments concerned, and participants were informed that all information would be handled with confidentiality and that no specific individual would be recognizable in the final result. Intensive care patients and their next of kin can be regarded as vulnerable. The interviews aimed at improving the care for ICU patients and next of kin, and even if this not was beneficial to those involved, it can hopefully serve the groups included. Taken together, the advantages were judged to outweigh the disadvantages.

With reference to Swedish law (SFS 2003:460), ethical approval was not considered necessary for this kind of interview study. As time passed, a local ethic committee was established in conjunction with local universities, and praxis was developed concerning applying for an advisory ethical review even for interview studies. Ethical review was then applied for from the local ethical committee for the studies on next of kin empowerment (II) and staff empowerment (III). All studies were performed in accordance with the Helsinki Declaration (WMA 2008).
FINDINGS

The findings of each study are presented below. Patients’ (I), next of kin’s (II) and staff’s (III) experiences are described, followed by patients’ experiences compared to next of kin and staff beliefs (IV). The structure of relationships, salient in every interview, is then expressed as circles of strength and power. An overview of findings from patient, next of kin and staff interviews is shown in Table 2.

Patient empowerment (I)

Patients’ conditions varied during their stay at ICU. The first period there was often characterized by a drowsy-like condition during which days and nights flowed together. The ability to communicate was greatly limited, and patients felt defenceless and dependent on the staff. The patients registered some information but did not ask, and seldom doubted, anything. When a patient’s condition improved slightly, he/she often became sensitive to staff moods. Sometimes an all-encompassing fight took place within the patient between giving up and dying or struggling to return to life.

A safe environment encouraging feelings of value and motivation, additional care, an encouragement of patient participation, and a strengthened and stimulated inherent joy of life and will to fight were all found to strengthen and empower the ICU patient. Depending on the patient’s condition, different structures were more or less salient. In general terms, when a patient’s condition was critical and his/her ability to communicate was very limited, experiences of a safe environment, generated by closeness, good care and information, were found to be most important to the patient’s experience of strength and power.

When the patient’s condition improved somewhat, strengthening and stimulating his/her own inherent joy of life and will to fight became central, and this was said to be of crucial importance for continued recovery. Even if the joy of life and will to fight were inherent in their personality,
Findings

this could be strengthened or weakened. The patients were influenced by the atmosphere and what was happening around them, including the cooperation within the care-giving team and the relationship between themselves, staff and next of kin. A patient’s feelings of value and motivation increased when he/she felt important as a person and was not “just a patient”, and when reminded about important things in ordinary life. Patients were also strengthened and empowered by additional care, feeling that someone truly cared for them and showed human warmth and consideration. Even if patients mostly wanted professionals to decide about their medical care, it was expressed as important to have some influence over everyday things such as their position in bed and personal hygiene. It was experienced as important to be taken seriously and be listened to. Next of kin played a very important role in contributing to a patient’s experiences of security, value and motivation, and in strengthening his/her inherent joy of life and will to fight.

Next of kin empowerment (II)

Experiences as next of kin of an acute, seriously ill intensive care patient strongly affected participants. The ICU period was sometimes expressed as the most terrible time in their life, but descriptions of this period as including the best experiences in life also occurred. Memories being mainly good or bad seemed to have less to do with the result of the care than with experiences of how it was performed. It did not help that the medical care and technical equipment were excellent and the next of kin did not become empowered, if not experiencing the patient and themselves being treated with human warmth and sensitivity. This also constituted a foundation for a trusting and supportive relationship, necessary for the empowerment process.

Perceptions of both a genuine will and a capacity to help and relieve were found to be essential for next of kin’s experiences of empowerment in an intensive care situation. The ability to be close to the critically ill family member was said to be of greatest importance, and their struggle to manage the situation was facilitated when they felt welcome at any time. A hug or a relieving conversation was often appreciated, and a question about how the next of kin felt could serve as an invitation to talk about feelings and experiences. Reliance on medical care as top quality was attained when
Table 2: Overview of structures emerging from patient, next of kin and staff interviews

<table>
<thead>
<tr>
<th>Patient empowerment in ICU</th>
<th>Next of kin empowerment in ICU</th>
<th>Staff empowerment in ICU</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strengthening and stimulating the patient’s own inherent joy of life and will to fight</td>
<td>A caring atmosphere with human warmth and sensitivity</td>
<td>Nourishing meetings</td>
</tr>
<tr>
<td>- Staff being careful, gentle and tender with the patient</td>
<td>- Staff being careful, gentle and tender with the patient</td>
<td>- With next of kin and patients</td>
</tr>
<tr>
<td>- Always feeling welcome and recognized</td>
<td>- Always feeling welcome and recognized</td>
<td>- Experiences of joy of life radiating from patient and next of kin despite illness</td>
</tr>
<tr>
<td>- Being treated with consideration and compassion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Creating a safe environment</td>
<td>Experiences of medical care as best possible</td>
<td>Feelings of doing good</td>
</tr>
<tr>
<td>- A human being close by</td>
<td>- Competent and caring staff</td>
<td>- Save life, decrease suffering, enable a peaceful death</td>
</tr>
<tr>
<td>- Continuous, well-balanced, professional information</td>
<td>- Medical and technical resources</td>
<td>- Often quick result</td>
</tr>
<tr>
<td>- Consultation with other specialists when applicable</td>
<td>- Consultation with other specialists when applicable</td>
<td>- Important driving force</td>
</tr>
<tr>
<td>Encouraging feelings of value and motivation</td>
<td>Closeness to the patient facilitated</td>
<td>Challenge, variety, speed and excitement</td>
</tr>
<tr>
<td>- Important as a person and not “just a patient”</td>
<td>- Allowed to stay at ICU as much as wanted</td>
<td>- Able to manage challenges</td>
</tr>
<tr>
<td>- Being reminded about important things in ordinary life</td>
<td>- Support with food and a place to rest</td>
<td>- Able to handle difficult conversations</td>
</tr>
<tr>
<td>Providing additional care</td>
<td>- Guidance, e.g., about where to sit and how to act</td>
<td></td>
</tr>
<tr>
<td>- Someone who really cares, howing human warmth and consideration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encouraging patient participation</td>
<td>Receiving continuous, straightforward and honest information</td>
<td>Increased personal knowledge and skills</td>
</tr>
<tr>
<td>- Taken seriously and listened to</td>
<td>- Each staff member has a special and important information area</td>
<td>- Continuous individual development</td>
</tr>
<tr>
<td>- Professionals decide about medical care</td>
<td></td>
<td>- Support, exchanged experiences, conferences and lectures</td>
</tr>
<tr>
<td>- Influence over everyday things, such as position in bed and personal hygiene</td>
<td></td>
<td>- Experiences of “flow”</td>
</tr>
<tr>
<td>Possibility to feel hope</td>
<td></td>
<td>Self-esteem and self-confidence</td>
</tr>
<tr>
<td>- Some little ray of hope encouraged</td>
<td></td>
<td>- Feeling valuable and safe both in self and in what one is doing</td>
</tr>
<tr>
<td>- Able to withstand and coach the sick family member</td>
<td></td>
<td>- Getting positive feedback</td>
</tr>
<tr>
<td>Support from other family members</td>
<td></td>
<td>- Proud of one’s profession</td>
</tr>
<tr>
<td>- Shared feelings and experiences</td>
<td></td>
<td>Good teamwork</td>
</tr>
<tr>
<td>- Company, practical help</td>
<td></td>
<td>- Positive engagement from everyone</td>
</tr>
<tr>
<td>Being involved</td>
<td></td>
<td>- Shared values and goals</td>
</tr>
<tr>
<td>- Allowed to be present, informed and follow development</td>
<td></td>
<td>Good atmosphere and organization</td>
</tr>
<tr>
<td>- Able to help, e.g., wet the patient’s mouth or bathe his/her forehead</td>
<td></td>
<td>- Cooperativeness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Room for humour</td>
</tr>
</tbody>
</table>
Findings

experiencing staff as competent and caring and as taking the necessary time, together with sufficient medical resources.

Anxiety and uncertainty caused energy loss, while continuous information and knowledge about the patient’s condition, treatment, analysis and future plans reduced next of kin’s anxiety, increased experiences of strength and power, and contributed to feelings of safety. Next of kin always needed to feel some little ray of hope, even if they understood that the situation was critical. Incessant travel, trying visits at the ICU, ongoing responsibility for ordinary work, home, pets and so on, made the next of kin exhausted and those who had access to support from other family members experienced this as valuable. Some participants also felt empowered when involved in the care process, by either providing some care, e.g. bathing the patient’s forehead or wetting his/her mouth, or just being informed and having the opportunity to follow the patient’s development.

Staff empowerment (III)

Participants were of different professions and hence experienced situations from different perspectives in some way, but despite this the meaning in their experiences was quite similar. Staff were found to be empowered both by internal processes such as feelings of doing good, increased self-esteem/self-confidence and increased knowledge and skills, and by external processes such as nourishing meetings, excitement and challenge, well functioning teamwork and a good atmosphere.

Meetings with patients and next of kin were experienced as one of the staff’s most valuable sources of energy and were also a factor that contributed to their choice of profession. Coming into contact with patients and next of kin and dealing with their histories sometimes left deep impressions and contributed to shaping a staff member’s personality and human growth. The opportunity to have contact with the patient was sometimes experienced as limited, but it was always experienced as strengthening when the relationship with next of kin was well functioning and natural. An important driving force in continuing to work at the ICU was the experience of being able to do something good for people, getting involved in treating and saving ill patients whose lives were threatened or decreasing their suffering, often with quick
Findings

results. Working in intensive care was experienced as worthwhile, exciting and challenging with its high speed and rapid changes, and managing something difficult and challenging was experienced as energy-generating. Continuous individual development, received through support from and exchanging experiences with colleagues and other professionals and through having the chance to take part in conferences and lectures, was considered important. Experiences of “flow” in the work generated a special kind of satisfaction. It was essential to feel valuable and safe both in oneself (self-esteem) and in what one was doing (self-confidence), get positive feedback and be able to feel proud of one’s profession. A good atmosphere with cooperativeness and room for humour was also expressed as strengthening.

Beliefs about patient empowerment (IV)

Both similarities and differences were found between patient experiences of empowerment and staff and next of kin beliefs about their experiences. The content and importance of each category sometimes differed between patient, next of kin and staff group, and all categories did not occur in all groups. An overview of all categories, subcategories and themes is shown in Table 3.

All three groups associated the patient’s experiences of strength and power with inner energy, but differences existed regarding how the energy was believed to be generated and promoted. The patients’ experiences of energy were strongly influenced by what was happening around them, and they were energized by nourishing relationships and a safe and caring environment. A relationship was experienced as nourishing when it included human warmth, commitment and mutuality. Even if roles and relationships between patients and staff were essentially unequal, episodes occurred when this reality moved out and the patient did not feel like just a patient but more like a member of the team, which could occur when sharing a joke or a chat, for example. Patients experienced this as highly empowering. They also recognized and enjoyed it when good teamwork existed within the staff group. Staff were experienced as competent when skilful and caring as well as providing valuable information. Next of kin were extremely important to patient’s experiences of safety, value, human warmth and motivation, and patients were strengthened when their next of kin were acknowledged and welcomed by the staff.
### Findings

Table 3: Themes, categories and subcategories from content analyses of patient experiences, next of kin beliefs and staff beliefs about patient empowerment

<table>
<thead>
<tr>
<th>Theme</th>
<th>Patients</th>
<th>Next of kin</th>
<th>Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joy of life and will to fight</td>
<td>Inner energy, promoted by nourishing relationships and a safe</td>
<td>Inner energy and a nourishing environment</td>
<td>Inner energy and safe and high quality care</td>
</tr>
<tr>
<td></td>
<td>and caring environment</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Subcategory</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimistic and strong as a person</td>
<td>Obstinate and strong as a person</td>
<td>Strong as a person</td>
<td></td>
</tr>
<tr>
<td>Pepped to not give up</td>
<td>Praise and stimulated</td>
<td>Will to survive</td>
<td>Psychological support/ Psychotropic drugs</td>
</tr>
<tr>
<td>Stay in a good mood</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual experiences</td>
<td>Energy through new insights</td>
<td></td>
<td></td>
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<tr>
<td>Hope</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Motivation</strong></td>
<td>Longing to return home and to ordinary life</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A great deal to live for</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pushed to exercise by staff and next of kin</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Feeling safe</strong></td>
<td>Next of kin or staff close by</td>
<td>Staff close by</td>
<td></td>
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<tr>
<td></td>
<td>Competent staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Continuity among staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Help quickly</td>
<td>Help quickly</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Beloved things</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Positive atmosphere</strong></td>
<td>Human warmth</td>
<td>Human warmth</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Caring spirit</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Peaceful environment</td>
<td>Positive attitude</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Good teamwork</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Self-esteem</strong></td>
<td>Recognized</td>
<td>Be seen and cared for</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Positive feedback</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relationship</strong></td>
<td>Mutual and respectful</td>
<td>Time and attention from family</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fellowship</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Familiar with staff</td>
<td>Time and attention from staff</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Commitment</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Individual and professional care</strong></td>
<td>Sensitivity to signals</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Shown respect</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Be seen and listened to</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Shown personal integrity</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Knowledge</strong></td>
<td>Passive receiver</td>
<td>One-way communication</td>
<td></td>
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<tr>
<td></td>
<td>Preparation</td>
<td>Short and limited</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Comprehension and explanation</td>
<td>Repeated</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Informed about current situation</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Questions answered</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Previous experiences</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Involvement in care</strong></td>
<td>Incapable</td>
<td>Neither capacity nor will</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Accept without reflection</td>
<td>Unaccustomed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Treated respectfully</td>
<td>Not in the acute situation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Be listened to and taken seriously</td>
<td>Very limited</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wishes and needs satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Some in daily care</td>
<td>Wishes mostly satisfied</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Usually too ill</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Next of kin believed that inner energy was an important factor for the patient, but this energy was regarded more as an inherent individual characteristic and as only possible to influence to a limited extent during the time in ICU. Next of kin strongly believed that a nourishing environment was the most important empowering factor to the patient. Time and attention from both next of kin and staff, a positive attitude, human warmth and beloved things were believed by next of kin to generate experiences of increased strength and power in the patient.

Staff also believed that inner energy was important to the patient’s experiences of strength and power, but even if they believed that having a great deal to live for and longing to return to one’s ordinary life generated motivation, they, as well as next of kin, seemed to regard energy as fairly stable and hard to influence during the patient’s ICU time. A safe and good quality care was believed by staff to be highly important to patients’ experiences of strength and power. There was, however, a clear distinction between the professional but respectful relationships emphasized by the staff and the more friendly and mutual relationship the patients described as highly empowering. Patients and staff also had different views on staff competence. While staff thought of competence as the capacity to perform medical and technical tasks in a reliable and accurate way, patients talked more about competence as skilfulness shown in the way staff talked to them and helped them in their daily care. Staff did not seem to believe that patients had as many experiences and memories from their ICU time as they actually had.

**The circle of strength and power**

Empowerment was found to include both internal sensations within the individual and external processes including interactions with others. Internal sensations were stimulated by external processes, however, and nourishing relationships were found to be of crucial importance and contributed to every participant’s experiences of empowerment, regardless of whether they were patient, next of kin or staff member.

When thinking of an empowerment process involving caring staff, next of kin and patients, it is easy to regard staff members as transmitters and the patients
and next of kin as receivers. However, findings in this thesis show that the empowerment process generates strength and power for everyone involved.

Patients were strengthened and empowered in their relationships with both next of kin and staff. Security, value, motivation and joy of life were generated in the relationship with a next of kin, who also served as a lifeline to ordinary life. The presence of next of kin reminded the patient of ordinary life and what he/she had to fight to return to. Feelings of safety were produced in relationships with staff that were always at hand, ready to help and inform. Patients were also strengthened when getting additional care, provided with warmth and consideration. Relationships with staff were experienced as highly empowering when a patient felt that he/she was not just a patient but more like a team member. This could be the case when sharing a joke or a conversation in a spirit of confidence.

While at home, next of kin often became anxious and upset. Their relationship and closeness to the patient, feelings of being able to coach and support the patient and feelings of hope when the patient showed signs of progress strengthened and empowered the next of kin. Nourishing relationships with staff, including warmth and sensitivity, compassion, support, maintained hope and being allowed to be involved, strengthened and empowered the next of kin. A relationship with room for everyday talks and even a joke or a laugh was often experienced as relieving when spending a great deal of time at the ICU. Relationships with caring staff sometimes caused them to remember this time at the ICU as one of the best times of their life, even if their beloved family member did not recover. A relationship with another family member, in which practical tasks and feelings of anxiety, sorrow and joy could be shared, was experienced as strengthening by next of kin who received this kind of support.

Finally, staff were strengthened and empowered in relationships with next of kin, patients and other staff members. Most empowering was the relationship with next of kin. It was experienced as both challenging and, when it worked out well, empowering to meet and support a next of kin who was in a trying situation. Next of kin often expressed gratefulness and appreciation in their daily contact with staff. This positive feedback, received in the relationships with next of kin, made staff members feel important and strengthened their self-confidence. Relationships with patients generated feelings of doing good, which were experienced as very strengthening and as an important driving
force for continuing to work in ICU. Staff experienced an inner satisfaction in seeing how well a patient felt when receiving extra care. The inherent inner strength of patients, despite serious illness, and the warm relationships between suffering family members, strengthened the staff members and made some meetings unforgettable. A great feeling of fellowship among staff at work was experienced as empowering, and good teamwork in which everyone played an important role increased the experience of strength and power, not only within the staff team but also among patients and their next of kin. A special feeling of “flow” could be experienced when relationships between all team members were optimal and everyone did their job in a professional manner and understood each other’s messages, even those that were not expressed.

Nourishing relationships generated increased self-confidence and feelings of value and motivation for everyone involved, and also generated inner energy. This inner energy was of essential importance to the ICU patients’ progressing health and recovery. It was also invaluable to next of kin’s ability to withstand and manage the situation and to staff’s work satisfaction and feelings of doing an important and valuable job. Relationships with patients and their next of kin also contributed to staff’s human and professional growth and development.

In this way, good and nourishing relationships constituted a circle of strength and power, involving patients, next of kin and staff members. Relationships and experiences of strength and power were influenced by the physical environment such as technical equipment, tubes and lines, sound and light. This could sometimes be experienced as disturbing, but also as contributing to security. Alarm machines were often experienced as disturbing, but a friendly and calm voice could generate safety and experiences of increased strength and power, as could skilful hands and someone close by. The circle of strength and power is illustrated in Figure 2.
Figure 2: The circle of strength and power in intensive care
DISCUSSION

Methodological considerations

An empirical phenomenological psychological method (EPP method) was used in the three studies reflecting patient empowerment (I), next of kin empowerment (II) and staff empowerment (III). Karlsson, who developed this method, claims that the validity of an analysis according to this method depends on the degree of success in the implementation of the partial phenomenological psychological reduction, which aims to ensure that the researcher does not impose his/her biases and prejudices upon his/her understanding of the text (Karlsson 1995). An attempt was hence made through the whole research process to stay as open and free from pre-assumptions as possible, and checks were continuously performed that findings had support in the interview text. According to Karlsson (1995), validity in the EPP method also depends on the horizontal consistency of interpretations, which means how well an identified meaning fits the meaning discovered in the rest of the texts. The fit was found to be quite good as most of the identified structures were revealed in every interview in the respective studies (so-called general structures). No contradictions were revealed between structures identified in some interviews (so-called typological structures) and the interviews in which they were not identified. The last validity criterion in the EPP method is vertical consistency, which refers to the consistency between different levels of the analysis (Karlsson 1995). Different steps in the analysis process and findings were continuously discussed within the research team to confirm the consistency and interpretations.

In order to facilitate the comparison, in the last study (IV) patients’ experiences were reanalysed using the same content analysis method used for next of kin and staff beliefs. When a text is analysed and reanalysed by the same researcher, there is a risk that the second analysis can be influenced by the first one. This could have been the case with the two analyses of patient experiences, even if an attempt was made to be as open and free from presumptions as possible during the second analysis as well. In order to verify
the validity of the analysis, repeated readings of the text parts and the whole combined with reflections were performed during the entire analysis process and the identified subcategories, categories and themes were repeatedly discussed within the author team.

Several discussions took place concerning whether staff interviews should encompass only one profession or include all professionals involved in the care for ICU patients. An apprehension was that empowering experiences might be far too different between different staff groups. As all professionals work together on the ICU team, however, it was considered valuable to capture the experiences of all three groups; even if the concrete situations in different staff stories were different, the meaning in their experiences was quite similar and no problems were experienced in putting their narratives together in the same analysis.

The findings in this thesis emanate from two common ICUs in southern Sweden and are probably transferrable (Polit and Hungler 1999) to similar kind of ICUs in places with a similar culture. A limitation was that only patients who survived the ICU period and next of kin who visited the ICU were interviewed. Transferability is therefore restricted to the included groups. On the other hand, some of the results, such as experiences of security, value, motivation, knowledge, hope and self-esteem, are probably to some extent in accordance with the general needs of human beings. The way these experiences can be encouraged is probably context-specific, however.

**Reflections on the findings**

The findings showed that relationships and interactions with others played an important role in participants’ experiences of empowerment, but empowerment was also experienced as an individual inner sensation. Here, some general findings are discussed and compared with previous investigations.
Discussion

Relationships

In this thesis, relationships were found to play an essential role in the empowerment process. Patients and next of kin were very sensitive to signals transmitted by caring staff. Next of kin became empowered when staff showed a genuine interest and tenderness for them and the patient, when their presence was appreciated and when staff attempted to interpret and satisfy their needs as well as those of the patient. The importance of relationships and atmosphere has previously been described, for example by Edvardsson (2005), who found that feeling welcome and being seen, as well as experiencing not only that you are being cared for but also that you are cared about, were valuable components in a caring atmosphere. Rushton (2007) advocated that when creating healing environments, we have to build up a workplace with authentic and respectful norms among patients, families and healthcare professionals. When environmental aspects are discussed within intensive care, an emphasis is often placed on the physical environment such as planning, colour, light, sound and pictures (Fontaine et al. 2001, Stichler 2001). Even if the physical environment of the care impacts the way it is provided, initiating and sustaining a therapeutic relationship with patients and their families is central in a caring and healing environment (Felgen 2004), and there is a need for further discussion on this topic within intensive care. Granberg et al. (1998) and Hofhuis et al. (2008) found that the presence of caring relationships, either with family or carers, had a positive impact on the patient in contributing to a decreased level of fear and worries and in enabling both care corresponding to the patient’s needs and professional satisfaction of staff (O’Connell 2008).

A clear distinction was noted between the professional but respectful relationship emphasized by the staff and the more friendly and mutual relationship described as highly empowering by the patients. Staff seemed to regard their relationships with the ICU patient as mainly one-way, while patients described a mutual relationship between themselves, staff and next of kin as highly empowering. Sharing a joke is one example of what the ICU patients experienced as increasing their feelings of mutuality and of being included in the team. Humour was not recognized by next of kin or staff as empowering to the ICU patient, while the patients themselves experienced humour as a valuable ingredient in a nourishing relationship. Humour has
been investigated only to a very limited extent in accordance with intensive care. Kinsman and Major (2008), however, recognized humour as important in building meaningful connections between ICU patients and caring staff. They also found that humour played an important role in relieving tension, developing emotional flexibility and humanizing healthcare experiences for both staff and patients in intensive care as well as palliative care. Humour, delivered with sensitivity and caring, ought to be seen as a valuable tool in creating friendly and mutual relationships even in intensive care (Kinsman and Major 2008).

Nourishing meetings with patients and next of kin and good fellowship with teamwork, positive engagement and shared goals were found to be important to ICU staff’s experiences of inner strength and power. This is in line with Brown’s (2002) theory that power in caring staff emerges through the quality of all their work relationships and that the quality of each relationship is important as a building block in the climates of teams, groups and organizations. Proenca (2007) found that a supportive team atmosphere and an empowering team context, with clear and jointly developed goals and an appropriate mix of competence, were positively associated with job satisfaction and organizational commitment. As good relations and teamwork have been proven to decrease the risk of burnout (Poncet et al. 2007, Emriaco et al. 2007) and increase experiences of empowerment (Brown 2002, Laschinger et al. 2001), this ought to be an important area for development work.

Knowledge and skills

Knowledge and skills were found to generate experiences of strength and power among participants from all three groups. Continuous, well-balanced professional information was found to be important to ICU patients’ and next of kin’s experience of strength and power. The ICU patient’s (Dyer 1995, Hafsteindottir 1996, Holland et al. 1997, McKinley et al. 2002) and next of kin’s (Alvares and Kirby 2006, Molter 1979, Verhaeghe et al. 2005) need for information is probably one of their most well documented needs.

Staff seemed however to view the patient as more unconscious and unable to participate in his/her own care and in the information exchange process than the patients themselves experienced. Several studies show that about 70-80 %
of ICU patients have clear recollections from their time in ICU, even if they do not remember everything (Hofhuis et al. 2008, Jones et al. 2001, Roberts et al. 2007, Rotondi et al. 2002). An important contributing factor to the discrepancy between patient experiences and staff beliefs is probably the fact that patients only refer to those times they have memory of, while staff refers to the entire ICU time. There is a risk, however, that staff may believe that the patient is not experiencing as much as he/she actually is, and is thus not attentive enough to be involved in their care to the highest degree possible.

Next of kin got strengthened when being able to interpreting the patient’s need and calm him/her down. Through guidance from staff, they received skill in how to act in the ICU environment, and some next of kin learned how to comfort the patient through bathing his/her forehead or wetting his/her mouth, which in turn empowered both the next of kin and the patient. The positive effect of involving next of kin in care has previously been highlighted by Eldredge (2005), who found that next of kin, through being involved in physical care, could demonstrate their love and affection for their seriously ill family member and at the same time feel less frustrated at not being able to do anything to help. Also, McAdam et al. (2008) underlined the importance of next of kin to be physically and actively present at the patient’s bedside and to be involved in care.

In the comparison between patient experiences and staff beliefs (IV) it was found that staff and patient had different views on staff competence. While staff thought of competence as the capacity to perform medical and technical tasks in a reliable and accurate way, patients defined skillfulness as the way staff talked to and touched them in their daily care. The importance of how ICU patients are talked to and touched has previous been described (Hofhuis et al. 2008, Granberg et al. 1998), but no study has been found that highlights patients’ and staff’s different views on competence. Patients and next of kin were found to be strongly affected by staff competence, i.e. not by what staff were doing but how they were performing their tasks. A soft and calm attitude calmed both patient and next of kin, while a stressed voice and manner made the patient and his/her next of kin anxious and distressed. In the same way, staff members have been found to affect each other. Cronqvist et al. (2005) found that some nurses were viewed as skilled in managing demanding and stressful situations, and when their colleagues worked with them it was easier for all nurses to manage stressful situations. The opposite was also
applicable: nurses who seemed nervous and uneasy in such situations influenced their colleagues in a negative way (Cronqvist et al. 2005).

**Power within oneself**

Power within oneself was, together with nourishing relationships, an important empowering factor in this thesis. All ICU patients regarded their own inherent joy of life and will to fight as their greatest strength. Similar findings seem not to have been highlighted before regarding ICU patients, although they have been among cancer patients (Bulsara 2004). This indicates that inner energy plays an important role in individuals being in a situation in which life is threatened. Current research also shows that a person’s joy of life and will to fight can be influenced by the environment and human relations, which does not seem to have been given any attention in previous research. This in turn highlights the importance of meeting these patients in a manner that makes them feel not only safe and cared for but also important and valuable as people.

Maintaining some small ray of hope, even if the situation was critical and the prognosis bleak, was found to be valuable for next of kin’s experiences of power within themselves. Similar findings have been described by Molter (1979) and Coulter (1989). According to Penson et al. (2007), hope is international and universal, and transcends resources and reality. However, ICU staff may be afraid of giving too much hope, and simultaneously satisfying next of kin’s need to feel hope and providing straightforward and honest information is a demanding task.

Feelings of doing good generated an inner strength to intensive care staff. It is known that compassion, love and social support have health benefits for recipients (Fingeld-Connett 2007, Stickley and Freshwater 2002), but their positive effects on the agents have received very little attention within health care. This has, however, been highlighted regarding volunteerism (Borgonovi 2008) and the elderly (Brown et al. 2003), and a correlation has been found between wellbeing, health, happiness and longevity among people who are emotionally compassionate, as long as they are not overwhelmed by helping tasks (Post 2005). It could be of interest to further examine the positive effects
on professionals of being compassionate and doing good, as well as how to prevent feelings of being overwhelmed.

**Self-esteem, self-confidence and self-determination**

Self-determination is often seen as an important factor in the concept of empowerment, but patients, next of kin and staff in this thesis did not mention self-determination as contributing to their experiences of increased strength and power. It was, however, important to feel valuable and safe in one’s self (self-esteem) and staff also needed to feel safe in what they were doing (self-confidence). Intensive care patients mostly wanted professionals to decide about their medical care, even if they considered it important to have some influence over everyday things. Being taken seriously and seen as a human being were experienced as empowering, however. This was also described by Hofhuis et al. (2008) as central and even lifesaving to ICU patients. Kieffer (1984) stated that it is the feeling and subjective experience that is important for empowerment, not the objective fact, and the level of self-determination was found to be quite well in accordance with the patient’s wishes.

**Quality of care**

In attempts to clarify the concept of empowerment, it has been discussed whether it is a process, a result, or both (Gibson 1991, Ryles 1999, Rodwell 1996). Some light could perhaps be shed on this discourse if empowerment were discussed in relation to quality of care. Donabedian’s (1980) well-known model of quality of care consists of the three components “structure”, “process” and “outcome”. This model can also be applied to the concept of empowerment. If we take a process component such as “Closeness between patient and next of kin is facilitated”, this could be enabled by the structure components “Open visiting policy, allowing next of kin to be near their sick family member” and “A place arranged near the patient where the next of kin is invited to sit without being in the way of surveillance and caring activities”. The outcome could be “Next of kin feels that closeness to the patient is facilitated to the desired degree”. It could also, together with other components, generate the outcome “Patient feels safe” and “Patient’s feelings
Discussion

of value and motivation are encouraged”. Process and outcome components are salient in the thesis while structure is more implicit, which is not surprising as data have been gathered from people involved in the empowerment process. If managers and leaders had been included in the interviews, the structure would probably have been more visible. If empowerment is seen as a dimension of quality of care, findings in this study ought to be taken into consideration to increase the quality of care in ICU.

According to Sandelowski (2004), qualitative research findings can serve as a window through which previous unknown aspects of life can be viewed or as a mirror to look back on and reframe own experiences. The findings in this thesis may serve as a basis for reflection about patient, next of kin and staff experiences of strength and power as well as about one’s own beliefs compared with participants’ experiences. A further step might perhaps be to develop an instrument aimed at measuring empowerment in intensive care. It could then be of importance to take into consideration the fact that bad is stronger than good, and that it may require several positive experiences to compensate for only one negative one (Baumeister et al. 2001). Based on this, there is perhaps a need to map not only empowering experiences but also the opposite kinds (cf. Faulkner 2001).

An intensive care department can be seen as a clinical microsystem. The essential elements of the microsystem include patients, staff, information and the care processes (Barach and Johnson 2006). Knowledge concerning clinical microsystems can guide and support peak performance. Improving clinical outcomes requires that the process be linked to the result. Previous research on clinical microsystems has identified ten success factors: Leadership, organizational support, staff focus, education and training, interdependence, patient focus, community and market focus, performance results, process improvements, and information and information technology (More et al. 2004). The patient-centric view of a health system is the foundation of development for clinical microsystems (Nelson et al. 2008). A high-performance clinical microsystem generates superb clinical care, based on science, compassion, and a specific and unique knowledge of what “this patient” wants and needs right now. These microsystems constantly use data to review their performance to monitor, manage and improve their quality. Knowledge about how to strengthen and empower the people included in the intensive care microsystem ought to be valuable in developing the intensive care clinical microsystem.
CONCLUSIONS

• Empowerment was found to include both internal sensations within the individual and external processes including interactions with other people. Internal sensations were, however, stimulated by external processes. Nourishing relationships were found to be of crucial importance, and contributed to every participant’s experiences of empowerment regardless of whether he/she was patient, next of kin or staff member.

• Patient empowerment in intensive care consists of strengthening and stimulating the patient’s own inherent joy of life and will to fight. A positive environment that encourages feelings of value and motivation and in which the patient feels safe, receives additional care and is allowed to participate to the degree he/she desires has a positive influence.

• An awareness about how essential it is to maintain the patient’s own inherent joy of life and will to fight emphasizes the need for personal care based on close communication with the patient and his/her next of kin in order to determine what is important for this patient in his/her daily life: What positive thing could he/she look forward to when going home? It also underlines the importance of a positive environment where next of kin are seen as invaluable resources.

• Next of kin in intensive care are strengthened and empowered by a caring atmosphere in which they receive continuous, straightforward and honest information that leaves room for some hope, and in which closeness to the patient is facilitated and medical care is experienced as the best possible. Some informants are also empowered by family support and/or participation in caring for the patient.

• Experiences from intensive care strongly affect next of kin, and whether memories from this period are to be mainly good or bad seems to have less to do with the result of the care than with their experiences of how it was performed.
Intensive care staff are empowered both by internal processes such as feelings of doing good, increased self-esteem/self-confidence and increased knowledge and skills, and by external processes such as nourishing meetings, excitement and challenge, well functioning teamwork and a good atmosphere.

When comparing patient experiences with staff and next of kin beliefs, there is agreement regarding joy of life and will to fight as essential to patients’ experiences of inner strength and power, but staff and next of kin seem to see this as a more constant individual viewpoint or characteristic than patients do.

Differences were found regarding the character of relationships between patient, next of kin and staff. A mutual and friendly relationship was experienced as highly empowering by the patients, while a more professional relationship was emphasized by the staff. Next of kin, and especially staff, seem to regard the patient as more unconscious and unable to participate in the communication and interaction process than the patient him/herself experiences.

Empowerment har beskrivits som en process för att öверvinna upplevelser av maktlöshet eller en modell genom vilken människor kan utveckla en känsla av inre styrka. Syftet med denna avhandling var att beskriva patienters, närståendes och personalns upplevelser av empowerment inom intensivvård. Syftet var också att jämföra patienters upplevelser med vad närstående och personal tror att de upplever. Med empowerment avses här upplevelser av inre kraft och styrka samt av delaktighet/självbestämmande.

Avhandlingen är baserad på öppna intervjuer med 11 patienter, 12 närstående och 12 personal vid två intensivvårdsavdelningar i södra Sverige. Ett fenomenologiskt perspektiv tillämpades i tre studier, medan den fjärde studien genomfördes med hjälp av en kvalitativ innehållsanalys.

Alla intensivvårdspatienter upplevde att den egna livsgnistan och kämparvilja var avgörande för deras upplevelser av inre kraft och styrka och inverkade på deras möjlighet att tillfriskna. Livsgnistan och kämparviljan påverkades i sin tur av vad som hände runt omkring patienterna. En positiv atmosfär där de kände sig trygga, betydelsefulla och blev lyssnade på, stärkte deras livsgnista och kämparvilja, liksom extra omsorg, uppmuntran och stärkt motivation. Närstående spelade en viktig roll i att förstärka patienternas upplevelser av trygghet, värde och motivation och öka deras upplevelse av inre kraft och styrka.

Atmosfären hade stor betydelse för närståendes upplevelser av kraft och styrka och de påverkades mer av hur något utfördes än av vad som utfördes. Det var viktigt för närstående att känna att det fanns både en kapacitet och en
vilja att hjälpa och lindra och de upplevde det stärkande att känna att personalen brydde sig såväl om patienten som om dem. En kontinuerlig, rak och ärlig information som lämnade rum för hopp, tillsammans med möjlighet att få vara nära den svårt sjuke familjemedlemmen samt en upplevelse av att patienten fick bästa möjliga medicinska vård, upplevdes av närstående som stärkande. Några stärktes även av stöd från andra familjemedlemmar och av att få vara delaktiga i vården.

Vårdspersonalen fick kraft och styrka både av interna och externa processer. Exempel på stärkande interna processer var upplevelsen av att göra gott, av att ha kunskaper och färdigheter för att klara de uppgifter och utmaningar man ställdes inför, samt av att känna sig trygg både i sig själv (självkänsla) och i det man gjorde (självförtroende). Närande möten med närstående och patienter, spänning och utmaningar, välfungerande teamarbete och en positiv atmosfär är exempel på externa processer som bidrog till personalens upplevelse av inre kraft och styrka.

När patienternas upplevelser jämfördes med vad närstående och personal trodde att de upplevde, fanns en samsyn i att patienternas egen livsgnista och kämparvilja hade stor betydelse för deras upplevelse av kraft och styrka. Närstående och personal betraktade emellertid patientens livsgnista och kämparvilja som ett tämligen statiskt karaktärsdrag, medan patienterna själva menade att livsgnistan och kämparviljan i hög utsträckning påverkades av atmosfären runt omkring dem och av hur de blev bemötta. Närstående och personal, tycktes betrakta patienterna som mer omedvetna och oförmöga att kommunicera och samverka med omgivningen än vad patienterna själva upplevde. Patienterna upplevde det som ytterst stärkande när de fick känna sig som medlemmar i vårdteamet och inte ”bara som en patient”.

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