Family members’ experiences of a diary kept during their sick relative’s stay within the intensive care setting.

Maria Johansson
Filosofie magisterprogram i omvårdnad 60 hp

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ABSTRACT

Background: A diary often helps the critically ill patient better to understand her/his illness and fill gaps in memory regarding their experiences in the ICU. To date there appears to be a lack of research that specifically focuses on family members’ experiences of the use of a diary within the intensive care setting. Aim: The aim of the study was to explore how family members experienced a diary kept during their sick relative’s stay in the ICU. Methodology: A qualitative methodology and, in particular, a hermeneutic approach were deemed to be appropriate for the study. Eleven participants were interviewed relating to nine diaries. Collected data have been analysed using hermeneutic interpretation inspired by Gadamer. Findings: Family members experienced that the diary sustained strengthened and deepened the connection to their sick relative and confirmed the presence of family members at bedside. The diary worked as a forum for mutual exchange of information between nurses and family members which led to a feeling of being united with the nurses in understanding. This in turn created a sense of togetherness and the family members didn’t feel neglected. In addition the diary was experienced as an implied hope that the outcome of the ICU stay would be good, thereby lending strength to worried family members. Conclusion: The diary was experienced as a tool that enhanced family members’ wellbeing.

Keywords: ICU, diaries, relatives, experiences, Gadamer, hermeneutics,
Filosofie magisterprogram i omvårdnad 60 hp

Närståendes erfarenheter av en dagbok förd under en sjuk släktlings vistelse inom intensivvården.

Maria Johansson

SAMMANFATTNING


Nyckelord: ICU, diaries, relatives, experiences, Gadamer, hermeneutics
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Appendix 1. Information om studien
Introduction

Traditionally research within critical care has tended to concentrate on the critically ill patient’s psychological well-being or family members’ immediate needs. In the field of psychological well-being there have been numerous studies investigating critically ill patients’ recall of the Intensive Care Unit (ICU) and classic work in the field such as that of Bergbom-Engberg and Hjalmae (1989) and Granberg, Bergbom Engberg and Lundberg (1998) suggested that approximately 50% of critically ill patients have no explicit memories of their experiences. It can be argued that these studies are still highly pertinent today.

However for those who do have clear recall of their experiences, common memories include pain and discomfort (Granberg et al. 1998, Samuelsson, 2006,) fear and anxiety (Granberg et al. 1998, Samuelsson, 2006) thirst (Li & Puntillo, 2006) and difficulty with communication (Granberg et al., 1998, Magnus & Turkington, 2005).

Although unpleasant experiences are commonly reported, positive memories of the ICU have also been documented, such as critically ill patients receiving reassurance from nurses and being made to feel secure, by Granberg et al. (1998) and more recently by Löf, Berggren and Ahlström (2008). The support of family members is described as being important because they are trusted and provide a link with reality. The relationship is able to facilitate communication between the critically ill patient and the nurses (Bergbom & Askwall, 2000, Granberg et al., 1998).

Nursing research in the area of family members’ needs has been conducted since the 1970’s both from qualitative and quantitative perspectives (van Horn & Tesh, 2000). Quantitative studies have often tended to focus on family members’ self-perceived needs and satisfaction
level using an instrument called the Critical Care Family Needs Inventory, CCFNI. The CCFNI was developed in 1983 by Molter and Leske by randomly re-ordering Molter’s original list of need items (Burr, 1998). The majority of the studies reviewed by Burr (1998) based on the CCFNI, demonstrated that the family members of critically ill patients need, honest, understandable and regular information about the critically ill patient’s treatment, progress, changes in condition and to feel that hospital staff care about the critically ill person. Although Burr’s review is more than a decade old, it remains to date a thorough and highly relevant survey of the studies available at that time point. Studies with a qualitative design included in this literature review reported similar findings from their respective textual analyses and involved the need for information, social support and hope. Current literature reviews (Paul & Rattrey, 2008, Verhaeghe et al. 2005) correspond with previous reports and any differences may be explained by variations in visiting local policies or cultural factors (Paul & Rattrey, 2008).

Burr (1998) examined coherence between the instrument CCFNI and a number of interviews. The results indicated convergence in many areas but there were also areas of divergence. The need of family members to support and reassure the critically ill individual was a common response to the overwhelming feelings of helplessness, which were apparent from the interviews but not from the CCFNI.

Qualitative studies using different approaches offer insight into family members’ experiences in the ICU. Engström and Söderberg (2004) expressed that family members are living in uncertainty as to whether the sick relative will survive or suffer from brain damage. In this state of uncertainty family members often disregard their own needs. Family members
commonly want to feel hope and it is essential for them to be able to feel some kind of hope even when the prognosis is poor.

Additional studies revealed a need to be at the bedside, to support and protect the sick relative (Engström, 2008, Engström & Söderberg, 2004, Lam & Beaulieu, 2004,) and to be reassured that the sick relative is receiving the best possible care (Lam & Beaulieu, 2004). Further, it has been shown that family members experience tremendous pressure when confronted with major changes in their lives because of the state of the sick relative (Ågård & Harder, 2007). Thus family members have to find a way to adapt to the new situation and the ability to adapt has in itself become an area of interest. A resent study by Söderström, Saveman, Hagberg and Benzein (2009) highlights that the adaptation is facilitated by the possibility to be near the sick relative, receiving supportive and unambiguous information from the staff.

An innovative way of conveying to the patient exactly what has happened during their time in ICU is to write diary (Bäckman & Walther, 2001, Engström et al., 2009, Storli et al., 2003). A diary, often with photographs, written by nurses and family members during the patient’s hospitalization on the ICU is becoming increasingly popular. This diary often helps the patient to better to understand her/his illness and fill gaps in memory regarding their experiences in the ICU (Bäckman&Walther, 2001, Engström, 2009, Storli et al., 2003).

Not quite ten years have passed, since Carl Backman and his colleagues wrote about the use of a diary and its impact on the patient. It can be argued that the focus within the literature thus far has been on the patient and the experience of the diary (Bergbom et al., 1999, Bäckman & Walther, 2001, Engström et al., 2009, Storli et al. 2003).
Nevertheless, within these studies there are some results about what the diary means to family members. Without the diary, the family has to repeatedly relive the trauma they have gone through by answering the sick relative’s questions about what happened in ICU. The presence of photographs of the patient at various stage of their illness is a concrete proof to them that the diary is telling the story in the way that it actually happened (Bäckman & Walther, 2001).

Bergbom et al. (1999) revealed in their pilot study that a diary kept during the patient’s stay in the ICU could be instrumental in supporting the family. She also highlighted that a diary can be helpful for families even after the critical period. The information in the diaries helps to fill the gap and makes the missing pieces fall into place. Therefore, it makes it easier for family members to accept what has happened and to understand the seriousness of the sick relative’s injury or disease. Further, Bergbom et al. (1999) and Combe (2005) reported that the diary seemed to open up communication channels between sick relatives and their families. Bereaved families also stated that they were pleased to receive a diary of the sick relative’s stay and glad to have something to look back on. They felt that they had some concrete memory of their loved one’s last days before they died (Bergbom et al. 1999).

Although the review of the literature described some results about what the diary means to family members, there appears to be a lack of research that specifically focuses on the family members’ experiences of the use of a diary within the intensive care setting. It is important to focus on family members’ experiences as they are important to the well-being of the patient, which is evident within the empirical literature (Bergbom & Askwall, 2000, Burr, 1998, Engström & Söderberg, 2004, Engström, 2008, Verhaeghe et al., 2005).
Aim

The aim of the study was to explore how family members experienced a diary kept during their sick relative’s stay in the ICU.

Family members in this study are defined as blood family or a close friend/partner. The patient in the ICU setting is also referred to as the sick relative. In this study it was important to find out how family members experienced an ICU diary. Did the diary help family members to feel involved in care of their sick relative? Did it help family members to feel that they were doing something worthwhile rather than being “left out”? Did the diary help family member to adapt to/coop with the sick relative’s changed health situation? Did it help the family members to have a closer relationship with the nursing staff?

Methodology

A qualitative methodology and, in particular, a hermeneutic approach (Gadamer, 1989) was chosen for the study as the aim was to gain a deeper understanding of family members’ experiences of the ICU diary. As there is a dearth of empirical research in this area, it can be argued that a qualitative method is highly appropriate (Starrin & Svensson, 1994). Hermeneutics are both the philosophy of understanding and the science of textual interpretation (Geanellos, 1998). In a hermeneutic text interpretation, the text is seen as a whole in which the dialogue between the reader and the text is intended to contribute towards a new understanding through the movement between the whole and the parts, namely the hermeneutic circle (Gadamer, 2002).

Dialogue, questioning and conversation stand at the centre of Gadamer’s philosophic hermeneutics and are portrayed as an interplay that is action-oriented. Conversation creates an
environment, which facilitates recognition. Recognition brings meaning and understanding to the text for the interpreter. The ultimate goal with this dialogue, questioning and understanding is to achieve a "fusion of horizons" between the interpreter, participants and the developed text (Gadamer 2002).

A fusion of horizons means that the researcher with experience has moved beyond his/her earlier understanding and is experiencing a new understanding. The previously incomprehensible has become more understandable. Gadamer also argued that although there can be understanding and agreement regarding a research question, it can never be fully understood. There is always something more that can be understood or "emptied of meaning" (Gadamer, 2002)

**Data Collection**

Qualitative data were collected by means of 11 audio-taped qualitative research interviews ranging from 35 minutes to 70 minutes in duration. In essence, hermeneutic interviewing is interpretive and not governed by pre-determined questions (Geanellos, 1999, Gadamer, 1989). This is because pre-determined questions establish the direction of the conversation instead of allowing the phenomena under investigation to do so. Thus, hermeneutic interviewers seek participative conversation between interviewees and themselves. This is because hermeneutics acknowledges that understanding proceeds through the interviewer’s pre-understandings not in spite of them (Geanellos, 1999, Gadamer, 1989). This means that the initial research question influences the whole research process and accordingly the guiding questions were as follows: *Can you tell me how you felt about the diary? What has it meant for you?* Then additional questions were asked to seek clarification of the interviewee’s story. In this way a co-creation of meaning occurs when the interviewer offers an interpretation of the
interviewee’s comment (Geanellos, 1999). The audio-taped interviews were transcribed verbatim to text files by the researcher for subsequent analysis.

**Ethical considerations**

The Ethical Research Committee in the south-east of Sweden (Etikprövningskommittén in Sydost) was consulted regarding ethical approval for the study and permission for the study was collected by the chief of the anaesthesia department at the local hospital. It is important to note that the interviewer is also an ICU nurse at the present clinic. It is acknowledged that there is a potential power relationship as the researcher has a dual role as nurse and researcher which is important to take into consideration with regards to the informed consent process. For example, it is possible that participants could be more positive than they really were about their experiences. In other words, that they were more likely to give socially desirable answers.

It can be argued that it represents both a strength and potential weakness when a researcher is familiar with the research setting (Hanson 1994). On the one hand, there can be a lack of objectivity in the study. However, at the same time knowledge of the setting may also be valuable for the research as it may lead to insights that enhance the richness of the data analysis, especially with regards to the research environment for example. Hanson, (1994) argued that it is important for the researcher to be aware of these issues. In this study, potential risks were minimized as those family members where the researcher had been directly involved were excluded from the study.
A potential benefit from participating in the study was that it could be therapeutic for the participants to talk about their experiences during the ICU. Often interviews can be a positive experience for participants as they are enabled to have time to talk about themselves and their experiences which is not always possible otherwise (Benzein et al. 2008). However, there was a risk that talking about their experiences might raise emotionally painful issues. The researcher had the possibility to offer support during the interview and also discuss with the participant if they wished to have further professional support and help.

**Participant selection/recruitment and procedure**

Eleven family members of patients from a general intensive care unit (ICU= setting) participated in the study. In total there were four men and seven women with an age range of 20-66 years, (see Table 1 for more details).

**Table 1 the profiles of the participants**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age</th>
<th>Relation</th>
<th>Patient illness</th>
<th>Duration of ICU hospitalisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Female</td>
<td>19</td>
<td>Granddaughter</td>
<td>Abdominal surgery</td>
<td>43 days</td>
</tr>
<tr>
<td>2</td>
<td>Male</td>
<td>20</td>
<td>Son</td>
<td>Cardiac arrest</td>
<td>6 days</td>
</tr>
<tr>
<td>3</td>
<td>Female</td>
<td>38</td>
<td>Daughter</td>
<td>Septicaemia</td>
<td>11 days</td>
</tr>
<tr>
<td>4</td>
<td>Female</td>
<td>63</td>
<td>Wife</td>
<td>Heart disease</td>
<td>19 days</td>
</tr>
<tr>
<td>5</td>
<td>Female</td>
<td>48</td>
<td>Wife</td>
<td>Cardiac arrest</td>
<td>6 days</td>
</tr>
<tr>
<td>6</td>
<td>Female</td>
<td>46</td>
<td>Daughter</td>
<td>Pneumonia</td>
<td>5 days</td>
</tr>
<tr>
<td>7</td>
<td>Female</td>
<td>35</td>
<td>Daughter</td>
<td>Cardiac arrest</td>
<td>19 days</td>
</tr>
<tr>
<td>8</td>
<td>Female</td>
<td>63</td>
<td>Wife</td>
<td>Heart disease</td>
<td>14 days</td>
</tr>
<tr>
<td>9</td>
<td>Male</td>
<td>50</td>
<td>Father</td>
<td>Respiratory failure</td>
<td>14 days</td>
</tr>
<tr>
<td>10</td>
<td>Male</td>
<td>57</td>
<td>Brother</td>
<td>Septicaemia</td>
<td>22 days</td>
</tr>
<tr>
<td>11</td>
<td>Male</td>
<td>24</td>
<td>Son</td>
<td>Septicaemia</td>
<td>22 days</td>
</tr>
</tbody>
</table>

Eleven participants corresponded to nine diaries as two participants were involved with the same diary in two cases. Inclusion criteria for family members were as follows: family
members in this study were defined as blood family or a close friend/partner, at least 18 years old, spoke Swedish, were willing to share their experiences and had had a family member in the ICU who had had a diary. Family members of persons with dementia, bereaved family members and also family members where the researcher had been directly involved in the ICU care were excluded. Four potential participants refused to take part in the interview study and two potential family members experienced the sudden death of their family member prior to the scheduled meeting and were thus excluded from the study.

The general ICU in this study is situated at a hospital in the south east of Sweden which was involved in practice development work with diaries in the ICU setting. A diary was kept when the patient had spent five or more days in the ICU. All patients, where a diary was kept in this practice development work were documented in a register. The participants were recruited on the basis of this register. The researcher carried out a purposeful sampling of participants in order to reflect variations in gender, age, length of stay in the ICU also in diagnosis of the patient to gain as broad an understanding as possible. The interviews were conducted six to ten weeks after the patient had been discharged from ICU.

The first step was to send out a letter to the selected potential participants (n=17) which contained clear, “easy to understand” information about the study (see Appendix 1). This written information clearly stated that the researcher would take contact by telephone in the next few days. Consequently, the next step was a telephone contact to provide verbal information about the study. Those who were interested in taking part were formally invited to participate in the study. A mutually convenient time and place for meeting and conducting an interview was arranged. At this time, participants were reassured that their participation was entirely voluntary and that they could withdraw from the study at any time.
The first interview was conducted in September 2007 and the final interview was carried out in March 2008. Eight interviews took place in a quiet room at the hospital and three interviews in the office of interviewees in their place of work.

**Data analysis**

When adopting a hermeneutic approach, it is important that the researcher brings her/his pre-understandings to consciousness in order to reflect upon them and take account of their influence upon the research process (Geanellos, 1998). However, Gadamer (1989) has a much more positive view of the value of identifying one’s pre-understandings. He considers that it is only through one’s pre-understandings that understanding is possible but if one does not recognise ones pre-understanding, there is a risk that one will fail to understand or will misjudge meaning.

The researcher reflected upon her pre-understandings of the topic throughout the study. As the study developed the researcher kept a diary about how her pre-understandings changed during the data collection and during the data analysis process. The researcher has spoken with her research supervisor and colleagues to identify pre-understandings and make them visible within this study: My pre-understandings can be summarised as follows.

The researcher:

- initiated the practice development work which involved providing patients with a narrative of their ICU stay in the form of a diary.
- was familiar with the theory that reading and re-reading the diary was therapeutic and might help the patient to recover from the trauma of critical illness.
was accustomed to meeting with family members and their former critically ill
relative to talk about their experiences of the diary
• had herself written in and read a number of diaries.
• had met one family member prior to the study where the diary was of a negative
  nature.
• is a specialist nurse in the ICU and familiar with the environment.

**Developing and naming themes**

Gadamer (1989) did not seek to produce a manual for guiding understanding in human
sciences because he saw hermeneutics as transcending method. Gadamer ironically wrote that
regarding study and research, “there are no rules and if they existed, I would advise not
following them” (Gadamer, 2002). The researcher used Geanellos (2005) as a model or
approach in the study and followed her steps and nomenclature since she explicitly stated
carefully outlined the hermeneutic approach she had adopted in her study (Geanellos, 2005).

The interpretation started by reading and re-reading the raw data to acquire a general sense of
how participants experienced the diaries (all interviews) in relation to its parts (individual
interviews). As Geanellos (2005) explained, at this stage, interpretation is in its infancy. The
text was then interrupted where the researcher found it contained a meaning unit. In this way,
the whole text (all interviews) was divided into meaning units and created a large column to
the left of the typing paper and then the first level of interpretation started, which was
*reduction*. This became the next column on the paper. Several thousand words were thus
reduced to several hundred specific meanings. Then the process proceeded on paper; meaning
units were highlighted guided by the aim in a green colour, due to the large quantity of texts.
The researcher worked with one interview at a time.
Back to the computer and the researcher worked with the highlighted meaning units and identified common elements and by so doing created the sub-themes. Grouping in sub-themes is described by Geanellos as ‘integration’ and was the second level of interpretation. When the researcher grouped the sub-themes, they were cut out and put in a new paper and named with an abstract word or meaning that captured the meaning found in all interviews. Then participants’ words were re-conceptualised to illuminate meanings and sub-themes found in all the interviews. Then sub-themes with shared meanings were clustered under themes and also here the researcher used the words of participants to name themes.

Finally, the focus was simultaneously on the fragments, sub-themes and themes and the whole text and formed the overall meaning by adding things together; a total. This process is called ‘aggregation’ by Geanellos (2005) which represents the third level of interpretation. This overall meaning was named ‘meta-theme’. The researcher used the words of participants’ and interpretive re-formulations to name the meta-theme (see Table 2 below).

**Table 2 example of data analysis**

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>First level of Interpretation; reduction</th>
<th>Second level of Interpretation; integration Sub theme</th>
<th>Second level of interpretation; words of participants</th>
<th>Third level of interpretation; aggregation Theme</th>
<th>Third level of interpretation, words of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Att liksom att de låg där bredvid honom hela tiden det kändes ju jättetbara liksom att även när jag inte är där så är ändå en del av mig där det kändes inte som man lämnade honom på samma sätt</td>
<td>Dagboken symboliserar den närståendes närvaro</td>
<td>Närvaro</td>
<td>Att man var där</td>
<td>Bibehållen relation</td>
<td>Hjälpte till att bevara en gemenskap</td>
</tr>
<tr>
<td>Det kändes ändå bra att han skulle veta att vi var där (betonar detta) ändå på något sätt det tror jag inte han hade förstått om han inte fått läsa det</td>
<td>Dagboken bekräftar närståendes närvaro</td>
<td>Närvaro</td>
<td>Att man var där</td>
<td>Bibehållen relation</td>
<td>Hjälpte till att bevara en gemenskap</td>
</tr>
</tbody>
</table>

12
Throughout all the interpretation process, the researcher reflected upon her pre-understandings and their influence on the interpretation and wrote field notes in a diary during the entire process. These field notes were also short stories about the perceived content of each interview. Many times during the study the researcher got ‘aha’ experiences. These experiences led to a new understanding, which were used in the subsequent interview. For instance the researcher gained access to unpleasant experiences and these were taken into account in the following interview.

The researcher has had in-depth discussions with her research supervisor in the course of the analysis process in order to find the main thread and achieve rigor in the findings. Sub themes were discussed and how they could be named. The original interview material has been read several times to make sure that the meta-theme, themes and sub themes were adequate.

**Findings**

The overall meaning that emerged was that the diary served an important purpose, in conveying an endeavour to sustain a connection with the sick relative throughout their stay in the ICU, summed up in the expression from a participant ‘it felt like contact’. Participants explained that their normal life-patterns were interrupted following the acute admission of their sick relative into hospital. The ICU was a new world with a new language and new culture. In this unfamiliar world, the diary became a tool to establish or to maintain connection with the sick relative, who often was unconscious or under heavy sedation. It became a link to the sick relative and participants experienced that the diary sustained, strengthen and deepened the connection. Further the diary helped participants to express what
it was like for them and their families and what the families had been through, whilst their sick relative was in ICU.

This overall meaning it felt like contact was represented by two themes and six sub themes. The meta-theme, themes and sub-themes are presented in Figure 1.

![Diagram showing the hierarchy of themes and sub-themes]

Figure 1. How family members experienced an ICU diary

Participants' words were used to name themes and sub-themes but those words illuminated the meanings in all interviews. Separately and together, these themes revealed how family members experienced an ICU diary. The themes and sub-themes are presented in the text that follows and are illustrated with quotations from the interviews.
Helped to maintain a feeling of togetherness.

The interview participants, their families and the staff on the ICU were pulling in the same direction and they all wanted the best for the patient. The sub themes ‘we were there’, ‘we had a task’ and ‘they cared’ highlighted the importance of being at bedside.

In most cases the sick relatives were unconscious or under heavy sedation and accordingly unable to communicate with the participants. Under these circumstances the diary became such a connection to the sick relative. In their endeavour to maintain connection, nothing was deemed to be too insignificant to report. They used the diary as a vehicle to tell about their experiences. In these narrations participants showed their care for the sick relative through their presence and hoped the sick relative really might feel this connection. Moreover the diary seemed to work as a testimony to the many hours of visiting, otherwise the participants were concerned that the patient might never have realized this.

...det största..ah..det var nog att få en kontakt med honom Fastän att man inte kunde prata med honom. Den känslan att han skulle veta hur det var för oss med eller hur det kändes att vi fanns där att han skulle veta det i efterhand på något vis. Det tror jag inte han hade förstått om han inte fått läsa det.

The participants wanted it to be apparent that they had been with them all the time and that the patient was cared for and loved and not abandoned.

'We were there'

The most important thing was to be near and maintain physical and emotional connection. All eleven participants said it was important to be with the sick relative and those who took up writing used the diary to convey the message that they really had been at the bedside when the sick relative was under heavy sedation. This presence was documented carefully in the diary.
The diary enabled visits to be described in detail as they happened. They told the same message repeatedly. ‘*We are here now at the bedside. We have just been away for a while eating lunch and then we are back again and you are looking a bit better*’. These small steps forward were joyfully received and documented in the diary.

One participant used physical contact in the form of hair and nail cutting as a possibility to be re-connected with the sick relative. These efforts were explained and described in the diary as a way to show an intimate and close relationship.

Each entry was dated and signed, sometimes again and again the same day. What time they came and left? Who was there? As well as what they were doing in an effort to help the sick relative. The need to be at the sick relative’s bedside was strong as they documented many times that they were sitting next to their bed and keeping them company.

It was important for participants that their thoughts and feelings were expressed and that their own concerns regarding the situation could be understood by the sick relative in the future. Hence the diaries became a method for conveying thoughts about how it was for the rest of the family. Participants had a strong desire to stay at their relative’s bedside, yet they were also concerned about children at home.

*Det är väl just det här att När han var som sämst då När han låg och inte kunde själv Och han kände att vi var där men just då var det skönt att man kunde skriva Det var ju det att man var där Att man fanns där Den känslan att kunna beskriva att jag var där, jag fanns där (betonar detta) När han hade det kanske som jobbigast Att man brydde sig att man bryr sig*
Participants experienced that they did something good by being at the bedside and that they were a valuable support. To be at the bedside was a spontaneous action that they were not always consciously aware of. Nevertheless, by writing in the diary they had been able to reflect on this instinctive presence and realized that it was good for both parties.

\[
\text{Att det är viktigt att man är där och det tror jag att det Samtidigt som jag tror att det var viktigt att man inte var där hela tiden alltså Att man var där under dagen För mig var det viktigt att vara där under dagen och kämpa med honom och att han fattade det alltså på något sätt så tror jag att han fattade det}
\]

Photographs were an aid in the phenomenon of being at the bedside. Photographs of the whole family at the bedside were of immense value for the participants whilst photographs of the sick relative alone were of less interest. The photos were proof in a visual way of actually being physically present. Every photograph told a story. One participant used the familiar quotation ‘a picture can tell more than a thousand words’ in order to describe the meaning of the photos.

\[
\text{En bild kan nog uttrycka en bild kan nog uttrycka mer än allt vad man skrivit för att vi fanns där alla tre det är min storebroer med Men det är klart han bor ju i L... så det är inte så ofta han kommer ner så bilderna betyder mycket för både mamma och mig}
\]

Some participants expressed a feeling of deeper relationships and closeness to each other when they had got photos of the whole family at the bedside in the diary. They were a real family that existed even though the actual circumstances may have been sad as a result of strained relationships with the sick relative or due to other problems. In this way the photographs and consequently the diary confirmed the presence of the family.

\[
\text{Det är också ett bevis på att man är familj på nån vänster både mamma pappa och jag på samma bild det är inte så ofta man blir tagen så jag kan kämma det är mer en son känsla med vi}
\]
For one participant the use of the diary was a symbol for maintaining relationships with their sick relative. In this way it wasn’t any longer necessary to be physically at the bedside all the time. It was legitimate to leave the sick relative; accordingly the diary became an extension of the participant. He had expressed his love, caring and the presence in the diary and this allowed him to leave the bedridden family member for the moment.

However there was a negative side. One participant in this study stated the ambiguity to the diary. The diary expressed a threat of something unpleasant in the way it pointed out the visiting patterns. In this way the diary provoked feelings of guilt because the visits weren’t often enough. Further, the participant stated that the diary caused symptoms of stress, because the participant didn’t know what to write and this created feelings of failure and a feeling of being insufficient in that if they didn’t write, the diary would make it seem that they were not at the bedside. To be absent was in this case equated with not caring about the patient which in turn could be a potential cause of conflict in the future.

The diary for this participant became a “weapon”, where the diary with its photos confirmed the presence at the bedside even if visits were rare due to a conflict full relationship. The
subtext being - I didn’t abandon you, when you were critically ill (even though you mistreated me in the past)

'Ve had a task'

In the beginning, the ICU environment was an unfamiliar setting and the participants didn’t know how to behave but the diary helped them to feel that they were doing something worthwhile and were not “left out”. The act of keeping a diary seemed to generate a sense of trust in that they had done something beneficial together with the nurses. Namely, to co-construct a story which would help the sick relative to make sense of what happened in the ICU?

Så kände man här sitter man och kan inte göra någonting Jag kan ju inte ens prata med henne för hon för annars kan man ju sitta och prata med dom och liksom lugna dom lite hon var ju nersövd i respirator då kände man sig ju verkligen ja hopp hm hm (suck med humor) Så jag tyckte det var bra det kändes som man hade en liten (betonar) uppgift.

The fact that both nurses and participants wrote in the diary made it a joint caring activity for the sick relative and via the diaries participants were incorporated in the care of the patient. When the doctor lifted sedation or the patient spontaneously became conscious, the participants used the summary in the diary to tell their sick relative about their state of ill-health and what had happened during the time they were unconscious. Several participants read out loud from the diary. The diary and its photos were considered as a document, which in an objective way portrayed what had actually happened.

One participant wrote in the early stages of recovery together with the sick relative in the diary.
Another participant was encouraged by the physiotherapist to write together with the sick relative so that their sick relative could practise his mobility with his hands. In this way the participants became a valuable support and had a feeling that they had an important job to do.

Several participants didn’t write in the diary but they had a task to do by reading or discussing what the nurses had been writing:

"Jag tycker alltså att dagboken var väldigt skön att ha både att man kunde följa sjuksköterskorna då alltså läsa lite vad dom hade gjort så att man blev mer inne i vad som hänt med pappa då när man inte är där det var ju skönt att läsa ändå att dom var där sen tror jag att i förhållandet till undersköterskor och sjuksköterskor fick man ett samtalsämne runt boken man satt ju så att man satt ju intill (betonar) varandra och länge så blev det som ett samtalsämne runt. Dom pratade om den och dom skrev i den och man läste det dom skrivit"

Participants experienced that the diary reduced their feelings of “being in the way”, when they were offered to write in the diary.

They cared

Participants’ perceived that the diary worked as a common platform regarding the sick relative and confirmed the nursing care that was carried out. Nurses took up writing in the diary and this created a feeling among the participants that the sick relative was unique as a person and was being cared for and valued. Nurses had seen and reflected over the sick relative in the writings. The participants realized that there was a lot of effort behind this writing and the diary made it obvious, that the sick relative was never alone. When the participants left the bed for a short time or for longer periods there were still nurses and
assistants at the bedside at all times. The photographic documentation with the nurses at the bedside was experienced as valuable information and confirmed their presence.

Moreover it seemed as if the diary opened up the way for fruitful discussions and developed them to get to know the nurses better and develop a closer relationship with each other. Nurses started to ask about grandchildren and their drawings or about something else that was written or glued in the diary. Participants talked about their own lives or about the patient as a person beyond this exceptional circumstance and this helped to create a feeling of togetherness.

This feeling of being united with the nurses in understanding, a sense of ‘we are all in this with you’ in helping the sick relative in turn helped one participant to lose his inhibitions as he wanted to take some pictures of his son, nurses and equipment in the room but he didn’t dare in case it was deemed to be inappropriate. He realized however that he was allowed to take pictures when the nurses asked his permission to photograph his son for photos for the diary. He became extremely talkative and by gaining permission from him to photograph made him feel involved in documenting how things really were at the hospital. After this event, he went on to take a lot of photos,

Det enda som jag ångrar så här efteråt är att vi inte tog fler bilder. Jag hade ju kameran med mig men det kändes så jävla påträngande och ta bilder när han ligger där jag visste inte riktigt hur personalen skulle reagera runt i kring där men sen gjorde ni det
där uppe och det gick alldeles utmärkt då och sedan nu då har jag haft med mig videokameran och filmat honom här.

This feeling of being united with the nurses created feelings of togetherness and the participants didn’t feel neglected.

**It made it possible to tell**

The diaries were experienced as a form of forum for participants, other family members, friends and the nurses and it seemed as if the diary temporarily substituted the usual opportunities to communicate. The participants interpreted the diary as a vehicle that enabled communication, despite the fact that their relative was under heavy sedation. Participants told about how day to day life was going on even if it was difficult. In their ambition to create a connection, they talked directly to the sick relative via the diary as if they were awake. Participants wanted to narrate about daily events outside hospital in order that their sick relative wouldn’t miss out on anything, no matter how big or small the particular issue was. This included events that the family during normal circumstances would have been talking about when going about their daily life.

*Det var ju mycket som hänt dom här dagarna när han varit borta Det var mycket man ville berätta för honom att vi har det bra då vi saknar dig och kom tillbaks Det är ju mycket så att det var ju vardagshändelser min bror sålde sin moped under tiden, så då skrev dom ju om det i dagboken Det var ju skönt att ändå det kändes som en våg att kommunicera med honom kändes det som*

Already during admission to hospital the diary worked as a forum for mutual exchange of information between nurses, participants and other family members. The need for information was inexhaustible and the diary became an additional source of information, apart
from the usual information from physicians and nurses. The themes ‘all’s well at home’, ‘how it felt’ and ‘so that you can really understand’ expressed the theme ‘it made it possible to tell’ but none of the writers expressed their feelings about death and brain injuries. They told about these misgivings in the interviews. However, they explained that they didn’t write down these thoughts in the diary.

All’s well at home

Participants wrote in the diary that things were all right at home but that the family longed to see him/her home as soon as possible. The underlying meaning was that they wanted their sick relative to be healthy and fill their regular place at home.

_Jag skrev det som hände hemma; nu har vi varit i trädgården Och gjort det och nu har vi gjort det och nu vill vi att du kommer hem...det var R som skötte trädgården ja visst det var han som var Trädgårdsmästare_

Some participants could express this experience of maintained communication explicit like that they had some kind of internal dialogue with their sick relative.

_Sen också om patienten är så nersövd man pratar ju ändå någonstans indirekt till den här personen när man är där och hålsar på och skriver i boken på något sätt så blir det så man pratar nog indirekt med den som är sjuk
det är en sorts dialog någonstans man skriver fast han är sovandes eller tvärtom skriver fast han är vaken
det är kanske just därför man går därifrån det kan ju värma när man ligger kvar_

Participants also wrote in the diary that their children were concerned about grandfather/mother and that they were thinking about him/her, because participants wanted it to be apparent that even smaller children cared about grandfather/grandmother. Younger
children did drawings and their parents glued them in the diary as a symbol of their love and care.

How it felt

The diary became a vehicle of expression for participant’s feelings or emotions about their sick relative in a positive way. Some participants could express deeper feelings than others which could be seen as a form of emotional or therapeutic writing. These emotional writings could be expressed as *det var skönt att få ner sina ord på papper*. This meaning was interpreted as a way to express their feelings, to write down their experiences, to create a meaning and coherence and in a certain sense reduce the inner stress they were experiencing. In this way it became an internal dialogue with their sick relative, where they explained their love. The diary made it easier to express strong feelings of love by writing them down these words which perhaps otherwise would never had been spoken, because it was seen to be so hard to say. In this way the diary was a comfort, helping to relieve inner stress about things which one participant had never verbally expressed before.

*Det kändes som om den hjälpte till att få ner sina ord på papper Att liksom att de låg där bredvid honom hela tiden Det kändes Det kändes inte som om man lämnade honom på samma sätt Orden så att säga för när jag väl är där liksom har Jag berättat att Jag är här Att vi saknar dig Behöver jag inte sitta bredvid honom hela tiden känns det som Utan det var ju jätteskönt*

Three participants expressed themselves in the diary which can be seen to be a form of emotional writing because it helped the participants to cope with their situation. A daughter described how she had to leave off her holiday because her father was admitted to hospital.

*jag berättade att jag hade varit utomlands och att jag åkte hem Vad som hänt och hur det kändes mycket Så det skrev jag ju mycket om hur det gick till Hur jag hade fåt reda på det och hur vi reagerade*
Another daughter spoke about initial chock and chaos and how it was hard to remember details. However, she had used the diary, as a reflective tool and had written down what had happened, what she had thought about and how her children had reacted. Details that she otherwise might have forgotten in the future but now she had remembrance of the time in the ICU by means of the diary.

Feelings, however that were verbalized, were principally of a positive nature for the majority of the participants because the diary was addressed to a family member who was expected to survive. In these circumstances, it was seen as being out of question to write about fear and threat of death. Instead, participants seemed to be holding the door open and looking forward, to the possibility that their sick relative would get better. They were fighting together with their sick relative by writing in the diary. This writing in the diary was the same as caring about and supporting their relative. The participants wanted to be the person who instilled strength and inspired with courage.

Participants during the course of the interview openly expressed that they had thoughts concerning death and brain injuries but they didn’t write about it in the diary. Feelings of fear however were instead in the disguise of a support. Nevertheless, they expressed that they could really feel death ‘breathing down the back of their neck’.

*och hon skrev pappa du ska bli bra du måste bli bra du ska bli bra vi ska klara det pappa pus och kram det skrev hon varje gång hon var liksom helt inställd på att pappa han blir bra det ska bara vara så ..... nu blir du snart bra pappa Nu kommer du snart hem*
Man sa liksom snälla krya på dig Fy fan va jobbigt det blev (mera gråt) det kom liksom tillbaka Vi längtar efter dig så att det var nog skönt att få ner det på papper liksom Och veta att det fanns där hos honom

However, for some participants the diary could be seen to be too public an arena to express their thoughts which could have lead to them giving up writing because they didn’t want to expose their feelings in front of others. They feared the worst but hoped everything turned out for the best, and didn’t want to write down about their worst fears for others to read,

Jag tyckte det var jobbigt att skriva om dom känslorna just då för samtidigt läste ju alla i den. Killarna (barnen) läste i den och på nåt sätt ville man i det läget vara positiv och tro att allting går bra hela tiden.....Utan varför jag tyckte det var jobbigt att skriva, så kunde man inte skriva det man kände, kände jag. Jag tyckte däremot det var skönt när andra skrev

One participant expressed negative feelings towards the fact that more distant family or friends were given access to the diary because the diary exposed intimate details. She experienced that the diary could harm the personal integrity, in this case a daughter, felt a troublesome situation, when the distant family read the diary at the hospital. She felt that her father couldn’t quite be trusted and he didn’t know what had happened himself.

Kanske där kan jag nog uppleva att han blev lite störd av att andra var i den På något sätt....på något sätt visste alla vad som hänt utom han och han kunde Inte läsa den eller orkade inte ta in det

So that you can really understand.
The diary reflected the course of time in an objective way and photos described in a visual way the environment, with its technical equipment. In this way the diaries were considered as a documentary presentation and created an overall picture. The nurses mostly repeated earlier
information conveyed by the physicians but they wrote the information in everyday language. This repeated information resulted in additional questions and further explanations about medical examinations and treatment of methods being asked by the family members and accordingly this led to a deeper understanding and more knowledge about the situation.

*Man läste ju den där först och sedan gick man och frågade Det var ju grejer man inte förstod. Det var mycket man inte förstod Under den tiden mycket lustiga grejer som hände värden hit och dit.*

The diary informed about visits of other family members and the state of health of the sick relative, when the participants had been for lunch or during night when they had been at home. Some participants highlighted the night nurses’ notes as especially important, because it wasn’t necessary to ask about everything when they came in the morning. Rather, they could read in the diary in the morning about what had happened during the night.

Later at home the diary assisted the memory in retelling the former sick relative about the course of events, especially if they were wondering about something specific. One participant used the diary as a comforting tool, when her husband couldn’t sleep well at nights. In the diary she could find, that it was the same problem in hospital.

All the participants said that they wanted even more pictures that portrayed the progress of their sick relative. Several of the participants used the diary to convince friends, fellow-workers to the sick relative and other family members about their sick relative’s state of health. Later even the sick relative him/herself had to be convinced about the serious situation, because he/she were often not able to imagine how they looked at hospital and the seriousness of the situation.
None of the participants felt that the photos were exposing too much. However, one sick relative didn’t want to show the photos but the granddaughter wanted to show the photos as a proof of the illness. In this instance, the granddaughter followed her grandmother’s desire not to show the pictures.

One participant used the diary in a different way, as she used the diary and its photos to warn her sick relative against the dangers of smoking. Her mother had been critically ill and survived her life threatening pneumonia and a few times she had had a craving for cigarettes, then the daughter had shown the photos.

To sum up; the diary was experienced by the majority of the participants as a tool maintaining contact with the sick relative and confirming their being at bedside, otherwise the participants were concerned that the sick relative might never have realized this. However, for one participant the experience of writing a diary proved to be a negative experience as the diary was a form of proof of the number of visits to her sick relative.

Participants saw the diary as a source of information but the diary also offered participants an opportunity to keep the sick relative informed of everyday life, no matter how small the events or occurrences may have been. In addition, the diary was experienced as a commission of trust and generated a feeling of being involved in nursing care. Moreover, by writing down their feelings it gave several participants an insight into their situation which was deemed to
be painful for them. Nevertheless, for these participants the diary became a tool for reflection. No fears about death were actually written down in the diary however as it was intended to be read by their sick relative in the future. Finally the diary was seen by the majority of participants to instil support, comfort and hope to their sick relative.

**Discussion**

The aim of the study was to explore how family members experienced a diary kept during their sick relative’s stay in the ICU. The study revealed experiences of endeavour to sustain a connection with their sick relative. One original finding which strengthens that the diaries sustained a connection to the sick relative was the family member who experienced the diary as a symbol for himself, which enabled him to leave his sick relative for a period of time. He allowed himself to take a break to eat and gather strength. In contrast, previous empirical studies have highlighted that family members often tend to neglect themselves during hospitalisation as they consider it is important to remain at the bedside in case there should be any change in their sick relative’s condition (Engström & Söderberg, 2004, Van Horn & Tesh, 2000). Thus, in the literature it is often reported that family members often set aside their personal needs and give priority to their sick relative (Burr, 1998, Verhaeghe et al. 2005).

Family members’ needs and concerns within the critical care setting have been thoroughly explored (Burr, 1998, Verhaeghe et al. 2005, Engström, 2008). Nevertheless this thesis highlights that the writing of a diary may suit family member’s needs in several ways; it acts as confirmation of being at the bedside, of being able to contribute in the care giving, maintaining hope and relaying understandable information. The findings from this study that the diary met the needs of the majority of family members has not been previously reported in other studies and in this way, this theses adds to our understanding of the topic.
It is well-known from previous studies that it is important for family members to be at the bedside (Engström & Söderberg, 2004, Lam & Beaulieu, 2004, Verhaege et al., 2005). However, in this study family members generally expressed a need to have their presence confirmed in the diary. This presence at the bedside was highlighted in text and supported by photos for the reason that they were firmly convinced that the sick relative might never have realized this otherwise. By so doing, the diary served a tangible proof having being at the bedside and sometimes with the subtext, ‘we are in this with you’.

Likewise the diary helped family members to feel involved in the care of their sick relative. At the same moment the family members took up writing, they were in a natural way incorporated in the care process and they felt they were doing some good.

It is said, within the critical care, that family members are able to provide a familiar, holistic and caring presence, which is qualitatively different from the caring presence of nurses and can, influence the outcome of the patient (Burr, 1998). Considering this statement the nurse has a key position in identifying family members’ need and could perhaps be able to use the diary as a tool to help family members to feel comfortable in the unfamiliar environment and to feel involved in the care of their sick relative.

Family members in this study experienced that they were given a mission and even a commission of trust. They had a mission to inform their sick relative about events occurring on the unit and significant events from the world outside hospital; thereby their sick relative wouldn’t miss out on anything. Other family members who were unable or unwilling to write in the diary had a task to do by reading or discussing what the nurses had been writing.
This finding demonstrated that the diary can be a tool to open up communication channels between the sick relative and their families which is reported in previous studies (Bergbom et al. 1999, Coombe, 2005).

The diary in itself was experienced as an implied hope that the outcome of the ICU stay would be good, thereby lending strength to worried family members. The assembled individual contribution that constructed the story which would help the sick relative to understand the intensive care stay created feelings of being united with the nurses in understanding. This is a new finding arising from this study and has not been reported before in the empirical literature.

Another important point concerning the diary was its ability to meet the needs of participants of understandable information that at the same time left room for hope. Often nurses repeated information previously relayed by physicians but in an everyday language and they explained about the medical treatment and what would happen the next day which inferred that the sick relative would survive. This information in the diary is available at all time. It is clear from the empirical literature that family members’ needs for comprehensible information are of paramount importance (Burr, 1998, Van Horn & Tesh, 2000, Verhaeghe et al., 2005). As Söderström and colleagues explained that comprehensible information facilitates adaptation to a changed situation (Söderström et al. 2009).

The researcher initially had a pre-understanding that the use of a diary in the ICU was wholly positive. However, the interviews led the researcher to an in-depth understanding of the complexity of using a diary and also to the realisation that keeping a diary can have a negative effect for family members in some situations. One participant responded negatively to the way
the diary pointed out her visits to her sick relative. This participant reacted to the diary with apprehension and fear that something unpleasant was going to happen in the future, because she felt that the visits weren’t often enough. This finding is in accordance with a pilot study by Bergbom et al. (1999) and raises the question, who should be encouraged to write in the diary?

On these grounds it can be argued that the nurse needs to take into account each family member’s unique situation and be aware that in some instances even though a diary is started, it may not be continued and that permission can be given by nurses to ‘scrap it’ or ‘forget it’ if they do not feel comfortable with it. It can also be suggested that in cases where there is known conflicts in the family, that the nurse is sensitive to this and treads very carefully and slowly introduces the idea of the diary and she/he discusses with family members the rationale of the diary, without the family members feeling duly obliged to write in the diary.

Research has been carried out both with family members participating in writing and with family members who have not participated in writing a diary in the ICU. In Norway studies have taken place without the participation of family members in the keeping of a diary (Storli & Lind, 2009) as in Denmark (Egerød & Christensen, 2009). In these studies, it is highlighted that the diaries are highly appreciated by the former critically ill patients. In Sweden, where family members participated Åsa Engström, et al. (2009) pointed to the value of family members notes and the personally way the diaries were written. Of particular interest is that these notes were perceived as the most important parts of the diary by the former critically ill patient. Likewise Roulin, Hurst and Spirig (2007) in a Swiss study highlighted that family members expressed their feelings in a more intense and deeply felt way than ICU nurses.
Another motivation for involving family members is that it can be therapeutic to write for some as this study has shown. A number of studies have demonstrated that when individuals write about emotional experiences, significant physical and mental health improvements follow (Pennebaker, 1997).

Further the diary helped some family member to adapt to their sick relative’s changed health situation because they had been able to reflect on the seriousness of the disease. The photographic documentation made the situation evident. This made it easier to take in account what had happened and thus to reconcile and accept the events. In so doing, the researcher argues that the diary may work as a kind of a debriefing tool. Bergbom et al. (1999) stated that the diary helped both patients and family members to integrate the ICU period into their own life histories and that the experiences and events were accepted as their own.

Another favourable influence on involving participants in writing the diary was the way they could establish the identity of the sick relative as a person, because they had a pre-existing relationship and by the diary conveying that the sick relative still was a human being and not “just a patient”. By writing in the diary both nurse and participants had seen the sick relative and reflected on the changed situation, where the sick relative was connected to technical equipment and influenced by pain and being under sedation. Thereby both participants and nurses were constantly reminded about the person the sick relatives were before they got ill, thus never reducing the individual to a diagnosis. This is in line with what Roulin et al’s previous findings (2007) who coined the expression ‘diaries are a caring activity’, which they took to mean have provided a platform for both nurse’s and family members’ performance.
At one level it can be argued that writing a diary is a simple and relatively inexpensive nursing intervention. However, there are several legal and ethical issues regarding the keeping of a diary, which have been previously highlighted by Egerod, Hvid Schwartz-Nielsen, Hansen and Laerkner (2007), and Egerod and Christensen (2009). These can be summarised as follows, should the diary include photographs? Can integrity be retained properly? How should the ambiguous ownership of the diary be handled?

In this study, all the participants highly appreciated photographs and the way they confirmed the presence at the bedside and they wanted more photos showing rehabilitation phase of their sick relative. Currently, there are no national guidelines regarding photographing for a medical diary in Sweden. In this study, the nurse asked family members for permission to photograph. However, one sick relative wanted to restrict the display of photos but the participant did not. Another uncertainty in photos of the patient, family members and health professionals is that they can be distributed on the internet by unthinkingly families.

The diary was considered the property of the sick relative by nurses and followed the sick relative to the general ward without any control regarding the content. The diary had also been made available to all visitors. Generally participants accepted these rules but one participant pointed out the easy accessibility and experienced the diary too intimate for less close friends. Another participant thought the diary was too public since she wanted to be seen as the strong one. Clearly the diary can be used in questionable situations which may fall outside the control of medical services.
Strengths and limitations

The study is based upon a small sample where the patient survived an ICU stay at a local hospital. As a result, the level of transferability of the findings of the study is questionable and subject to discussion. It is likely that the findings of this study may only be transferable to other similar ICU care settings where a diary is kept, and where the health care system is similar to that in Sweden. Nevertheless, the study has led to a deeper understanding about how family members experienced an ICU diary kept during a sick relative’s stay in ICU.

It is important to note however that the participants were still in a vulnerable situation and some gave short interviews, in which they were tearful or openly cried. Perhaps the participants responded to the researcher as someone outside of their situation, a more neutral person with whom they could open up to. The researcher was then initially unprepared for their responses and found it quite challenging to cope with the depth of their emotions. In this way, it can be argued that in the earlier interviews she experienced a sense of role confusion, namely, her new role as a qualitative researcher versus her earlier more familiar role as nurse (Hanson, 1994). Thus, during the earlier interviews she was unsure of how to act and respond. Nevertheless, it developed into an instructive process and the researcher was more 'feeling her way' and learning about being a qualitative researcher and hadn’t realised how close she would engage with the participants.

Participants probably experienced the interview situation as a positive experience since they were enabled to talk about themselves and their experiences. The conversations flowed without pre-determined questions and through the researcher’s contextual knowledge, which led to a deeper understanding of the complexity of the diary as a phenomenon. This is in line with hermeneutics that acknowledges that understanding proceeds through the interviewer’s
pre-understandings (Gadamer, 1989, Geanellos, 1999). It must be seen as a strength that the participants highlighted negative aspects that the researcher was not previously aware of.

The contextual knowledge can be seen as both a strength and potential weakness. The researcher knew how to ask the right questions that led to deeper understanding and to enhance the richness of the data analysis. On the one hand the researcher constantly had to be aware of her pre-understandings in order not to be blind to weakness in her work or take anything for granted. Consequently, it can be both a strength and potential weakness when the researcher also holds the role of nurse in the ICU setting.

Another limiting factor is the timeframe of the study. The interviews were carried out at one period and the analysis process took place at another period in time. The entire process has been taken place over the course of a three year timeframe. It can also be argued that the researcher has learnt a lot in this time and she has also been able to analyze the data thoroughly and also reflect on her pre-understandings carefully. This may not have occurred to the same extent if she had carried it out in a much shorter timeframe.

An additional strength was that the researcher carried out a purposeful sampling of participants in order to reflect variations in gender, age and length of stay in the ICU. Four potential participants refused to take part in the interview study and the reason will remain unknown. It can be speculated that these potential participants experienced something traumatic and found it stressful to meet a nurse/researcher. However, they had the courage not to participate instead of giving socially desirable answers (Hanson, 1994).
It can be argued that the study was too small to be able to discuss possible differences in the effect of keeping a diary on relatives according to their different relationships. For instance, is it more positive for spouses than it is for adults children? Also, does age play a difference and also the length of duration of stay in the ICU? All these factors are very interesting but these factors are more suitable for study in a larger quantitative study.

**Practical recommendations**

The following recommendations for clinical practice arising from the study are tentative in nature given that the study was small-scale:

- a local checklist be prepared in point form how to best involve families in diary writing to prevent that the diary should be misused in the future. This to make known the importance of adopting an individual approach and the nurse and family members exploring together if they feel keeping a diary would be beneficial or not. Should the diary include photographs? How to retain integrity properly? Who should write in the diary?

- a pamphlet focusing on patient/ family members’ immediate needs and concerns in the ICU be prepared and how to help families prepare for their time in the ICU setting.

- a nurse with specialist knowledge of family members’ needs to act as a contact person for other staff to provide emotional support and promote a family focused approach within the ICU setting.

**Implications for research**

The findings of this qualitative study have led the researcher to the following recommendations,
• further studies in the field are required. In particular, a longitudinal study to gain an insight into the importance of the keeping of a diary from the viewpoint of relatives over time. Perhaps the diary has more long term effects, for instance, one year later or two years later.

• further additional studies be carried out with the intention to examine how family members experience the diary, where the critically ill did not survive the stay in the ICU. These would complement the results in this study.

• It is important that family members have someone to talk to, who has the expertise and can provide emotional support to the entire family. For this reason, it would be interesting to explore how the diary affects the nurse in her profession role.

Conclusions

The diary was experienced as a tool that enhanced family-wellbeing as it met the needs of the majority of family members in this study in a variety of ways: confirmation of being at the bedside, being able to contribute in the care giving and relaying understandable information. Finally, the diary was experienced as an implied hope that the outcome of the ICU stay would be good, thereby lending strength to worried family members. Still, the diary had negative implications for one family member and this was due to the nature of her previous conflict full relationship with her sick relative, which highlights the need for a more individualised approach to the use of a diary with family members of patients within ICU.
References


Du tillfrågas härmed om deltagande i en studie.

Vill Du delge Dina erfarenheter av dagbok på intensivvårdsavdelningen
– en intervjustudie med närstående

Under hösten 2007 kommer jag att göra en studie på Länssjukhuset i Kalmar med syfte att undersöka närståendes erfarenheter av dagbok på intensivvårdsavdelningen. Positiva och negativa erfarenheter om detta ger sjuksköterskor viktig kunskap som i sin tur kan förbättra stödet till närstående.


Ditt deltagande i studien är helt frivilligt. Du kan når som helst avbryta ditt deltagande utan att motivera varför. Det kommer inte att påverka den vård och omsorg som din närstående får.

Studien är en uppsats i omvårdnad vid Humanvetenskapliga institutionen, Högskolan i Kalmar. Ev. kommer studien att redovisas i artikelform för publicering i en internationell omvårdnadstidskrift

Jag kommer inom några dagar att kontakta Dig via telefon.

Har Du några frågor är Du välkommen att kontakta någon av nedanstående.

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