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ORIGINAL ARTICLE

The experiences of patients and their families of visiting whilst in an intensive care unit – A hermeneutic interview study

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KEYWORDS

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Summary

Aim: The aim of this study was to interpret and understand the meanings of the lived experiences of visiting of patients in an ICU and their families.

Method: The research design was hermeneutic, based on interviews. This study includes 12 interviews with seven patients and five relatives who had been in an ICU. The interview text was interpreted in a Gadamerian manner as different plays with actors and plots.

Findings: Patients' narratives could be divided into two parts; recall of real life and unreal life experiences, the unreal being more common. Relatives' narratives are described as being on stage and being backstage, i.e. in the room with the patient and outside it.

Conclusion: The final interpretation elucidated the experience of visiting as the sudden shift between being present in real life vs. being present in the real life of unreality. It was a process whereby the patient and the family build a new understanding of life that creates a new form of interplay within the family. The pre-critical illness life is no longer there – a new life has begun. To support patients and their families in this process of change a family-centred care perspective is necessary.

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Introduction

The present study is the third part of a major project aimed at gaining a deeper understanding of hospital visits from the perspective of patients in an intensive care unit (ICU) and those close to them (Eriksson and Bergbom, 2007; Eriksson et al., 2010). Current research has accumulated a growing body of evidence concerning the importance of visiting the ICU and the patient seen from a family perspective.

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Restricted visiting hours are neither longer recommended, nor are other restrictions such as exclusion of small children or on the grounds of risk of infection (Knutsson et al., 2004). The patient and family feel best if the interplay between them is as normal as possible. The professionals have a critical role in this interplay, as shown in several studies, as they set the rules governing the interplay in the room, give information about which visitors would be appropriate and how many family members should be in the room at any one time (Almerud et al., 2007; Eriksson and Bergbom, 2007; Eriksson et al., 2010; Söderström et al., 2006; Takman and Severinsson, 2005).

Earlier studies have provided professionals with knowledge about what the critical ill patients and families remember from the care in the ICU. Many patients have vivid memories of unreal experiences and a slight paranoia that may cause them problems post-ICU care. There are also patients who have no or very few, memories of the care in the ICU, which can also be a problem for both the patients and their families. Providing caring actions aimed at preventing the development of such negative memories and experiences is complex since it is the medical condition as such, drugs and not least the caring environment itself that influence memories from ICU care. Studies concerning health-related quality of life and patients show that it takes a long or a very long time to return to life as it was before the ICU stay (Orwelius et al., 2008; Ringdal et al., 2009, 2010; Samuelson et al., 2007).

One intervention that has been shown to have a good effect on recovery after being cared for in an ICU is keeping a diary for the patient, in which professionals, family and visitors write about the patient's time in the ICU. The diary, with a follow-up meeting, has been an established caring intervention in the Nordic countries and Great Britain for some years now. The follow-up meeting is often arranged as follows: patient and family receive a telephone call inviting them to a follow-up meeting with the professionals, about two months after leaving the ICU. The diary, with photographs taken during the care period, is returned to the patient and the professionals guide the family through the diary and the photos. The purpose is to help the patient to remember their time in the ICU and for the family to get answers to any questions they have. The opportunity to visit the room where the patient was cared for has been shown to help the patients to anchor their dreams in reality (Bäckman et al., 2010; Egerod and Christensen, 2009; Gjengedal et al., 2010; Griffiths et al., 2009; Knowles and Tarrier, 2009; Storli and Lind, 2009; Åkerman et al., 2010).

The interplay within the family is not, however, much explored in current research. A recently published study, by Nelson et al. (2009), shows that an early meeting between the family and the professionals during the first 78 hours of care has a great impact on the wellbeing of the family and there was better compliance with mutual decisions about the patient's care. The use of a deliberately family-centred care model formalises the status of the patient and the family as the unit of care and feelings of respect, collaboration and support are enhanced (Mitchell et al., 2009).

Söderström et al. (2009) has in a hermeneutic interview study, found three phases of the families' adaptation to the

new life. These comprise striving for endurance, striving for consolation and striving to rebuild life under new conditions. These findings provide more evidence for the importance of "family-centred thinking" on the part of the professionals. To see the patient and the family as whole, whilst simultaneously being able to recognise risk behaviours in some of the family members, has become a great challenge for the caring personnel in ICUs. A silent and/or shut-in family member who is unable to participate in the family interplay can create an asymmetry within the family that could hinder their adaptation to a new life (Mitchell et al., 2009; Nelson et al., 2009; Söderström et al., 2009).

Patients and families themselves define their families. In this article the word "family" refers to two or more people who are related in any way – biologically, legally or emotionally. We use family, next of kin, close ones, loved ones and relatives interchangeably in our text.

The intention in this study was to gain an understanding of the meaning of visiting for those who are really concerned – patients and their loved ones who have been stricken by unexpected, acute serious illness/injury. What have the patients experienced and what do they narrate concerning their memories of their family members visiting during their time in the ICU? What do the relatives believe they have given to the patients? What was the nature of the interplay between family and professionals during and/or in the period after the time in the ICU? What significant influences does the caring environment have?

Aim

The aim was to interpret and understand the meanings of the lived experiences of visiting for patients cared for in an intensive care unit and for their families.

Method

This study used a hermeneutic method. Both Gadamer (1989) and Løgstrup (1962) describe texts as a dimension of art; texts create scenes, allowing us to observe from the outside in the same way as in a theatre. This concept was used in the analysis in an earlier hermeneutic observational study by Eriksson et al. (2010) and was considered to be very useful in interpreting observational data. This study aims to continue the development of this method for the interpretation of interview data obtained from patients cared for in an ICU and their relatives. This approach was considered suitable as the interviewees created scenes and narratives when they told their stories. In order to reflect on notes and transcripts from the interviews we used a "lens" or pre-understanding, based in the tradition of nursing and a theoretical framework in caring sciences as both nurses and researchers (Phillips, 2007). During the interpretation process there was a fusion of horizons concerning various pre-understandings and experiences within the research team and also between the horizon of the text and that of the interpreters. Reflecting on the text – as various scenes or paintings describing the patients' and their close ones (who are the characters) experiences – brings a new understanding, consistent with Gadamer's (1989) ideas.

Participants and setting

A total of 12 interviewees, seven patients who had been in an ICU and five relatives who had visited, were invited to participate in a research interview. The interviews focused on narratives of their experiences and memories of receiving visitors, visiting and being visitors during the period in the ICU. The interviewees were aged 20–68 years. Both patients and visitors were interviewed to gain insight into and understanding of the meaning of “visiting”. An earlier study by Eriksson et al. (2010) had focused on the interplay between patients and their visitors and those findings prompted questions about “visiting” in the present study.

Of the seven patients, four were invited to participate in this study when they were recruited to participate in the second study in the larger research programme. Three patients were invited when they attended a regular, planned follow-up visit to the ICU with their close ones. Six of the patients were men and one was a woman. Five relatives were involved in the study, three of them were spouses and the other two were parents. Three of the relatives were men and two were women. The relatives participated in the opening study and/or in the ICU’s follow-up programme. The patients invited to participate met the following criteria: ≥ 18 years old, acute admission due to critical illness/serious injuries, ≥ 48 hours in an ICU, mechanically ventilated for ≥ 24 hours, with at least one visit from a next of kin. The four patients who participated in the initial data collection process followed a deeper sedation regimen whereas the other three patients had “light” sedation. Patients with head injuries, psychiatric diagnoses and intoxication were excluded. Patients and relatives received verbal and written information about the study and were asked to voluntarily participate in a tape-recorded interview. They were free to withdraw at any time and were guaranteed full confidentiality.

Data were collected at a university hospital in Sweden with a regional referral area covering approximately 1.8 million inhabitants. The ICU has 12 beds and admits adult patients suffering from medical and surgical conditions and trauma. The patients are cared for in two-bed rooms. One critical care nurse (CCRN) and one enrolled nurse (EN) are allocated to every two patients; however the CCRN has overall caring responsibility. There is an open visiting policy at the ICU based on an agreement with each patient’s allocated CCRN.

Data collection

Data were collected using a qualitative research interview approach (Kvale and Brinkmann, 2009). The first author conducted the interviews carried out at the hospital between two and eight weeks after the patients’ discharge from the ICU. Two patients had been discharged from the hospital and returned home at the time of the interviews. Three patients and their relatives were interviewed during a following-up visit to the ICU. For four of the interviews the patient and close one were interviewed together as a pair. In the remaining six interviews the patient and relatives were separate. The interview approach and the diversity in the interviewee’s roles and relationships resulted in maximal variation

(Polit and Beck, 2006) concerning the data set and provided rich and dense descriptions. An initial open-ended interview question allowed the interviewee to talk freely from the start. The question used in the present study was “Can you please tell me what you remember of your stay at the ICU – especially concerning visits?” The qualitative research interview resembles an everyday conversation but has a specific goal (Kvale and Brinkmann, 2009). During the conversation the interviewer followed the interviewee and tried to guide the conversation to produce a picture of both patient’s and relative’s experiences of the time in the ICU. Thus a narrative was created that might reveal information relevant to the aim of study. This dialogue is a process intended to reveal the deeper understanding crucial for an interview in a Gadamerian approach (Phillips, 2007). All interviews were tape recorded and transcribed verbatim.

Interpretation and analysis through the hermeneutic circle

We started the reading from a philosophical, existential perspective (Gadamer, 1989; Løgstrup, 1962). The first step in the interpretation process was to read the text as a whole but separating the patients’ and relatives’ perspectives. This was done to obtain a sound analysis and to contrast the perspectives. With this aim in mind we started to look for how different scenes/pictures were outlined by the storytellers. All these scenes were then transcribed to form a new text that revealed a deep understanding of the lived experience of visiting in an ICU. The next part of the process was to search for similarities and differences in these scenes. What are the relatives’ stories like when they talk about the visits and the interplay with their loved ones? What is the plot, scene and who are the characters, etc.? During the interpretation process it became clear that in the patients’ narratives most of the stories were about unreal experiences, nightmares and/or hallucinations. The next step in the hermeneutic circle was to interpret these scenes and to unfold a comprehensive understanding of them. The stories told by the close ones included scenes describing visits where the loved one had talked about murder, kidnapping and fishing boats etc. It was important to analyse these unreal experiences because they constitute the patient’s state of being, sometimes throughout a long period in the ICU and even after leaving it.

There is always tension, interplay, between the whole and the elements in an interpretation (Debesay et al., 2008). After dividing the text into different parts and then interpreting them – we put the parts together again and found a deeper and more comprehensive understanding of the meaning of the experiences of visiting in an ICU from a family perspective, i.e. we temporarily closed the hermeneutic circle.

Results

The final interpretation is presented in two parts, namely: patients’ and relatives’ experiences. Both relatives’ and patients’ experiences are divided into more scenes. Each

section starts with a description and concludes with the final interpretation.

Patients' experiences

Most of the patients had no or few real memories from their time in the ICU. Even if the relatives had told them and said that they behaved normally they were unable to remember it themselves. However, all patients remembered fragments that emerged during the dialogue with the family, during the interview or during the follow-up meeting at the hospital.

Recalling real life experiences

The patients remembered that their family had been at their bedside almost all the time. It was very important to feel that security even if they were sometimes unable to understand why they were there or who the visitors were. In real life experiences the patients remembered the family and that they were by their side during the struggle to return to life. The family encouraged them to fight for their lives.

"I think that the presence of the family yes... very much... yeah they eh, I was not alone, it was tremendously important, it really was"

Getting well and going home are thoughts they remembered from their stay in the ICU. It was a sort of personal commitment that they had to fight this battle and return to life. Those who had been more awake when in the ICU said they had to show their family that they could do things such as sitting in a chair. They wanted to show they had made progress and were ready to return to life.

"In the morning I sat there in my chair and waited for them to come I would struggle to sit up before they came"

Other memories were of other patients in the room and that they were behind a curtain that separated them from their neighbour. None of the patients had unpleasant memories of the room or the environment.

The diary, kept by both staff and relatives, was appreciated by the whole family after discharge from the ICU. During the ICU time, writing down what happened was a kind of therapy for the family members; afterwards they could start the process of working through their experiences by reading these notes. The diary's most important function, especially for those who did not remember so much, was the opportunity it gave for remembering or providing scenes to fill the gaps in the memory from the ICU.

Recalling unreal life experiences

No patient had no memories at all, even if they made this claim at the beginning of the interview. All started to remember when the talk turned to their treatment period in the ICU and very often they remembered unreal life experiences. They described scenes aboard a boat on a journey with a cold wind blowing around them. The patients talked of feelings of escaping or being taken away on trips to different places – a kind of hunting or chasing. They felt that

they had died or were dying and been blown up in an explosion. Some experiences were so frightening that they were unable to express them verbally – those memories were just etched in as dark feelings.

The following story is an example of such an unreal life experience told by one of the patients. This story was almost an action movie and the storyteller was totally consumed by it. It started with him being a subject in an experiment in the hospital where his DNA was manipulated to create a super human. The hospital worked with a company and they had to hide him in various places in the town in safe houses. His relatives were part of the conspiracy against him, even if they tried to calm him. The story about this experiment was a sensation in the press and the hunt to find him escalated over time. He witnessed people being killed beside him and he was given various drugs to prevent him from talking. The whole story ends in a battle where his wife and father are killed before his eyes. This traumatic, unreal experience is almost a form of torture that follows him constantly even after discharge from the ICU. That part of the story is characteristic of many stories told by other patients.

Relatives' experiences

The relatives who participated in the interview were in various phases of reaction to the critical event, which influenced their experiences as visitors. During the analysis we could see two different scenes appearing; the first "being on stage" represents the time when the family was present in the room with the loved one. The time/situation describing what happened in between and afterwards, i.e. when they left the room has been conceptualised as "being back-stage".

Being on stage

Initially it was a struggle merely to survive the sudden shifts between hope and despair, expressed by the relatives as being in chaos. The importance of being well informed cannot be over-emphasised; all interviewees described their search for information, usually with good results but not always. It takes strength and courage to ask questions, because you can get unwanted information or no information at all.

The relatives' situation when the loved one was unconscious and there was no response to visiting was characterised by frustration. They sought any hint of reaction from their loved ones and tried to communicate with them. A small movement under the eyelid or a turn of the patient's head or hand movement signalled hope that the loved one could once again perceive them. It became important to be there when the loved one woke up; a moment of true happiness and love that they longed for.

During those long hours of visiting a need sometimes arose to be a part of the caring team and help the nurses to care for the loved one with simple things such as replacing the probe for the measurement of oxygen saturation or moistening the loved one's mouth. It felt good to be able to do something, to be needed and able to help. On the other hand there were relatives who were absolutely not interested in participating, rather taking on the role of

guardian of the patient to ensure the professionals made no mistakes.

The *being on stage* period was a turbulent time centred on thoughts about life and death and being tossed between hope and despair. Sitting for endless hours at the bedside, with nothing happening and no contact with the loved one because they were unconscious was devastating for the entire family. All interviewees said that the most important thing during their stay in the ICU was the interplay with the staff. The events most described occurred when the interaction between family members and staff has not worked. Building a trusting relationship with the staff was very important and the most effective way to achieve this was through continuously receiving information about the treatment and progress of the loved one. Being able to feel assured that the staff would do their utmost, brought relief. The relatives had no unpleasant or frightening memories of the environment in the room, rather the opposite. Technical equipment and connected tubes gave them the feeling that the professionals were doing everything possible and the patient was well taken care of, which inspired confidence and security.

Being backstage

The relatives repeatedly described the importance of the family for their wellbeing. The family members' support allowed them to cope and helped them to take breaks from the vigil they kept at the bedside all their waking hours. A walk in the hospital park made them think and focus on good thoughts. One story described a walk in the hospital park

"...then I saw all the snowdrops – and they were the first things my husband brought into me when we lived on xx – street, he always picked the first ones for me – then it hit me, then I completely broke down ... I just sat there in the park and cried for hours... and it was good to cry – but it was hard. Then I went and stood outside the window of his room and I tried to look up and send him warming thoughts"

The critical event could even improve existing poor relations in the family and bring it together. Being suddenly alone making big decisions in daily life outside the hospital was hard, as in the case when a partner who had shared everything earlier could no longer participate in everyday decisions.

It became impossible for some families especially when they lived far away to stay at the hospital and visits had to be replaced by telephone calls. That was perceived as a very difficult situation and increased the importance of continuity in the relationship with staff that could also work via the telephone.

Life outside the room and ward, i.e. *being backstage* can be summed in two scenes – family and obligations – the family made sure they were relieved of their vigilance, were there to comfort in good times and bad. The second scene – obligations – was the reminder that a lot of things had to be done in everyday life even as their nearest and dearest was fighting for life. The distraction of doing everyday things was good because they were able or forced to think about other things. Dependence on the interplay with the

staff could create a feeling of either trust or mistrust or a feeling of security knowing that the staff would contact them if anything happened to their loved ones. The family was of the utmost importance in making it possible to endure the suffering. Contact with visitors to the other patient in the room and other visitors met in the corridor, opened the opportunity for dialogue, which was perceived as supportive. They got to know and could support each other in the demanding process.

Discussion

The findings in this study show that there are differences in the narrations of patients and family about experiences from visiting in the ICU. An earlier observations study by Eriksson et al. (2010) showed that family–patient interplay is initially problematic when the patient is sedated or even unconscious. Our interpretation of this finding was that the patient was trapped by his/her body and the family was unable to interplay with their loved one, because they were unable to understand the new signals (Eriksson et al., 2010). Both the patient and the family described this problem, but for the patients the biggest problem was to remember their stay in the ICU at all. They had memories of their family having been in the ICU and that it was very important for them, giving them a feeling of security and the hope and courage to struggle to survive. The unreal life experiences predominated as has been seen in findings for decades; Bergbom Engberg (1989) described it at the end of the 1980s. What has happened since? Now it is time to attempt interventions to prevent these unreal life experiences as some patients carry them with them for the rest of their lives. Jones et al. (2009) in a randomised controlled trial have shown that there is evidence that keeping a diary during the ICU stay, with follow-up meetings, can prevent lifelong suffering. Discussion about what the sedation regimes do to the patient is current. Various regimes has been tried, i.e. ceasing sedation once a day (Girard et al., 2008) and keeping the patient at a sedation level of MAAS 3–4, i.e. awake even during mechanical ventilation (Karlsson et al., 2010).

One of the most important findings when the family was "on stage" was the need for good interplay with the professionals. It was crucial for going "backstage" that they dared to trust the staff. This is in accordance with Burr, 1996, 1998; Happ et al., 2007; Hupcey, 1999; Molter, 1979. One strategy used to create this interplay is the unit's adoption of a family-centred philosophy of care (Davidson et al., 2007; Mitchell and Chaboyer, 2010; Mitchell et al., 2009; Mitchell, 2008), including the following core concepts: dignity and respect, information sharing, participation and collaboration. Applied to the care for children this has worked for many years and we have to look and learn from such developments in care.

The findings about the caring environment surprised us as in earlier studies by Almerud et al. (2007) and Levy (2007) both patients and families described the environment and the machines as frightening.

In the present study both patients and family set scenes where the caring environment was positive, the machines mediated security and, moreover, that the staff were doing everything they could to save the loved one. Only one ear-

lier study, Fridh et al. (2009) supports our findings in adults. One reason could be that today there are many reality series about hospitals on the television and people are more used to high-tech caring environments and connect them with positive feelings. Knutsson et al. (2008) described this earlier in an interview study with children visiting an adult ICU. Children have vivid imaginations and hearing stories told by adults they could produce pictures that are worse than the reality. It is important to stress that this finding provides no basis for halting the much needed development of the caring environment in new ICUs.

Critique of the method

Performing the analysis in steps gives strength to the interpretation, as does the fact that three researchers (two senior) read the material and interpreted it together, giving the result a strength and trustworthiness whilst limiting the risk of over-interpretation. The limitation in this study is that the sample of 12 persons may be considered too small but the narratives produced rich, dense descriptions with variations in the characters of both patients and relatives. The reason the sample is small is that this group of people are vulnerable during a long time after the ICU care and mortality amongst these patients is high. Those who survive and their close ones are also hard to locate and contact for a follow-up interview. This explains why the patients in the study came from such a wide referral area. The findings cannot be generalised, but the interpretation of how patients and their relatives describe their experiences of visiting can be used by the caring staff to bring a new understanding to their meetings with patients and relatives in other contexts. This is what Gadamer terms "fusion of horizons", when your pre-understanding meets another way of understanding, which then changes to a new understanding (Gadamer, 1989). Not all patients and relatives were matched however; the focus was not on the interplay of visiting but on the meaning of and in visiting. Nevertheless, a "comparison" of what visiting meant for each part may have been captured. It was sometimes felt that it was inappropriate and ethically inconsiderate to ask for an interview.

During the research interview the focus was mostly on the patients' experiences, i.e. the interviewer tried to give more space to the patient. However, there were some parts in some interview situations where the relatives dominated the conversation more. This can be considered as a weakness but also strength as the relatives' involvement often helped the patients to remember and put words to situations that were hard for them to talk about. From our point of view they created a shared whole. We found, however, that during the interviewing, apart from the research process, a healing process took place in the retelling of the participants' experiences. Those who started the interview with "I do not remember anything" finished with memories of which they were previously unaware.

Conclusion

The conclusion is that the dynamics of visiting in an ICU comprise the sudden shift between being present in reality (real life) vs. being present in the real life of unreality. It

is a process whereby the patient and the family construct a new understanding of life creating a new form of interplay in the family. The realisation that the life before the critical illness has gone and a new life have begun came to both patients and families during the visiting. The interplay was considered as important to both patient and the family. However, the fact that the time spent "backstage" also exists is crucial because this is one way for the family to gain the strength to manage to be "on stage". The time backstage also gives the patient time to sleep and recover. Visiting helps the patient and the family to share what the illness/injury and the time in the ICU time did to their lives. The findings in the current study point to the benefits of having follow-up meetings with patients and their families. We argue that such conversations – even a research interview – provide an opportunity to jointly work through memories – or the feeling of having no memories – together with professionals. We see it as crucial to help the patient and relatives to connect their various stories after the treatment period and, moreover, to help them to bridge the gap between unreal and real memories and experiences of being on stage and/or backstage. This means sharing a story amongst the family and professionals and seeing ICU care practice holistically where the patient and the family are met as one entity.

Conflict of interest

The authors have no conflicts of interest.

The study was approved by the Research Ethics Committee of Gothenburg University (S012-03).

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