Strange and scary memories of the intensive care unit: a qualitative, longitudinal study inspired by Ricoeur’s interpretation theory

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Aims and objectives. To describe the content of former intensive care unit patients’ memories of delusions.

Background. Intensive care unit patients often have strange and frightening experiences during the critical stage of illness. Earlier studies have provided small-sample in-depth descriptions of patient experiences in intensive care unit, but large-scale studies are also needed to inform intensive care unit follow-up.

Methods. The study had a qualitative design using phenomenological hermeneutic analysis inspired by Ricoeur’s interpretive theory. Patients were assessed with Confusion Assessment Method of the Intensive Care Unit for delirium in intensive care unit, and after discharge, memories of delusions were described by 114 of 325 patients in face-to-face (after two weeks) and telephone interviews (after two and six months) using the Intensive Care Unit Memory Tool.

Results. Four themes emerged: the ever-present family, dynamic spaces, surviving challenges and constant motion. Memories of delusions were a vivid mix of fact and fiction, demonstrating dynamic shifts in time, place and motion, but not dependent on the presence of delirium assessed by Confusion Assessment Method of the Intensive Care Unit.

Conclusions. Analysis based on Ricoeurian phenomenological hermeneutics provided insights into themes in intensive care unit patients’ memories of delusions. More studies are needed to understand the meaning of memories of delusions, the commonality of themes and the association between delusions and delirium after an intensive care unit stay.

Relevance to clinical practice. Understanding patients’ memories of delusions is beneficial to nurses caring for patients that are anxious, upset or agitated. It opens a window to the world of the patient who is unable to communicate due to intubation and general weakness. We recommend the provision of nurse-led intensive care unit follow-up enabling patients to describe and discuss their intensive care unit experiences.

Key words: delirium, intensive care unit, memories, narratives, nursing, phenomenological hermeneutics

Accepted for publication: 1 April 2016
Introduction

At the bottom of the ocean, a truck moves along at great speed, with doors and windows in constant motion; meanwhile the staff is planning how best to kill the patient. Does this sound bizarre? Nevertheless, these experiences are common after a stay in the intensive care unit (ICU), and the memories might have lasting impact on the patients. These memories are not only unpleasant, but present a challenge for the patient when hospital staff and relatives doubt the reality of the experiences, as when a patient was very angry in the ICU with his relatives because they would not believe that the staff got drunk and did not take care of patients at night. Later he realised that the relatives were right, and he felt very ashamed.

Background

Many ICU survivors experience stressful memories traumatizing life after hospital discharge (Samuelson et al. 2006). Memories of ICU can be experienced as pleasant or unpleasant (Samuelson 2011), and might persist for years (Storli et al. 2008, Zetterlund et al. 2012). Intrusive memories in post intensive care patients have been categorised as factual, hallucinatory/delusional or uncertain (Wade et al. 2015), according to the patient’s ability to distinguish between fact and fiction. Factors such as delirium, confusion, sleep disorders and sedatives potentially contribute to delusional memories and symptoms related to post-traumatic stress syndrome (PTSD) (Croxall et al. 2014). Delirium is a confusional and often fluctuating state experienced by patients in the ICU, whereas intrusive memories are memories that persist in the ICU survivors. Delusions are thought to arise during delirium caused by sepsis, hypoxia, sleep deprivation or medications (Wade et al. 2015). Patients have described emotional pain associated with remorse, guilt or shame after being delirious in the ICU (Pollard et al. 2015). Recall of stressful experiences in the ICU has been associated with the development of psychological distress (Samuelson et al. 2007a,b).

Research on the experience of ICU survivors has focused on the impact of memories rather than descriptions of their content. A qualitative review of studies of ICU memories identified the following eight themes: transformations of perception – unreal experiences and dreams; proximity to death; transformation and perception of the body in illness; transformation and perception of time; the critical care environment – technology and dependence; care, communication and relationships with healthcare professionals; the support of family and friends and desire for contact; transfer from critical care and recovery from critical illness (Cutler et al. 2013). A phenomenological study demonstrated that delusional ICU memories could be meaningful to patients who had internalised the memories as real bodily experiences (Storli et al. 2007). Traumatic memories have been associated with the symptoms of PTSD (Jones et al. 2001, Samuelson et al. 2007a,b), but the association is inconclusive (Nouwen et al. 2012). Recent studies have failed to confirm the protective role of factual memories on the development of PTSD (Kiekkas et al. 2010, Svenningsen et al. 2015a). A recent study found that patients with lighter or no sedation still experienced memory gaps and delusional memories (Burry et al. 2015).

Large-scale studies focusing on the content and meaning of ICU memories of delusions are lacking. Knowledge from this type of studies might potentially support patients, family and staff in understanding and dealing with these haunting memories that are the mainstay of intensive care and critical illness. The aim of the study was to describe former ICU patients’ memories of delusions. We have chosen to use the term ‘memories of delusions’ to indicate that the patients are aware that their memories are unreal; we refer to delusional memories as unreal experiences that are believed by the patient to be true.

Methods

Design

The study had a qualitative explorative design using an approach of phenomenological hermeneutics to text analysis inspired by Ricoeur’s interpretation theory (Dreyer & Pedersen 2009). The method consists of several levels of interpretation: naïve reading, structural analysis and critical analysis and discussion. Within this paradigm, we wish to present and discuss a means of creating distance between the text and interpretation by including a narrative in literary prose illustrating the comprehensive interpretation of the interviews as described by Dreyer and Pedersen (2009).

Setting and participants

This study was part of a larger study on sedation and delirium in adults admitted >48 hours at three medical-surgical ICUs in Denmark. The three ICUs had 1:1 staffing and no physical restraints were used. Data were generated at several time points during and after the ICU stay: delirium was assessed in the ICU using the Confusion Assessment Method of the Intensive Care Unit (CAM-ICU) (Ely et al. 2001). After ICU discharge, the patients were contacted at
the time points: at two weeks \((n = 279)\) either bedside or by telephone and two months \((n = 265)\) and six months \((n = 244)\) by telephone. In total, 325 patients answered at least one ICU Memory Tool (Jones et al., 2010), and 214 of them answered at all three times. Interviews at two weeks after ICU discharge were either conducted bedside at the ward or by telephone (Svenningsen et al., 2014) by the first author or one assistant, when participants were assessed without delirium. Of the 325 patients interviewed, the 114 patients who described memories of delusions when responding to the ICU Memory Tool were included in the present study. The patients were \(57\%\) male, \(59\%\) surgical, mean age 61 (SD 15) and \(56\%\) were CAM-ICU positive (delirious) at least once in the ICU.

Data generation

All questionnaires were answered in dialogue with the investigator to ensure patient comprehension. If patients answered ‘yes’ to one or more of the four indicated delusions in the instrument (dreams, nightmares, hallucinations, a feeling that someone is trying to hurt you) they were asked to go on to answer questions 4c and 4d (Jones et al., 2000):

1. If you had any feelings that someone was trying to hurt or harm you while you were in intensive care can you please describe these feelings?
2. If you had nightmares or hallucinations while you were in intensive care could you please describe these?

ICU memories are not just dreams, they are ‘unreal experiences’ that are recalled by the patient after the ICU stay. We assume that the patients were aware that the memories were delusional when we conducted the narrative interviews, hence the term ‘memories of delusions’.

Notes describing the narratives from answering these two questions were taken by the investigator during the interviews and read subsequently to the patient for validation. For patients that were interviewed more than once, data were combined as one narrative per participant. These narrative notes are the units for analysis. Two patients declined to discuss their memories because they were too unpleasant, while the rest of the patients described their memories although it might have been uncomfortable. Most patients expressed relief that someone wanted to hear their ‘crazy stories’ although the interviews were not intended as therapy. In many cases the interviewer was the first, and sometimes only, person to hear their narrative. To ensure rigour in capturing participants’ perspectives, the narrative interviews had an approach, where the interviewer was an open and attentive listener, avoiding interpretation at this

Strategy of analysis

The meaning of memories of delusions in the ICU were analysed in depth in the present study, and we offer our interpretation of these memories to add to the knowledge-base of patient experiences in the ICU. Our comprehensive understanding of the 114 patient narratives of ICU memories is described in the four themes: the ever-present family, the dynamic space, surviving games and experiments and the constant motion (Table 2).

Analysis started after all interviews were transcribed using a phenomenological hermeneutic approach of text analysis (Dreyer & Pedersen 2009) inspired by Paul Ricoeur’s (1984) interpretation theory. The first and the last authors initially conducted analysis. The first author entered with a preunderstanding of in-depth knowledge of the patients, the interview text and the local context of ICU care and treatment. The last author entered with in-depth knowledge of the method of analysis and only a superficial and theoretical preunderstanding of the ICU context. According to Ricoeur, interpreting a text means seeing something new in what is already taken for granted, and disclosing a new kind of ‘being-in-the-world’ (Ricoeur 1973a,b, Dreyer & Pedersen 2009). With different preunderstandings, we were able to challenge each other in the interpretation process enabling us to see something new.

Table 1 Number of memories of delusions according to timing of interview

<table>
<thead>
<tr>
<th>Number of memories of delusions</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>After two weeks, (n) (% with delirium)</td>
<td>143 (51)</td>
<td>67 (54)</td>
<td>59 (59)</td>
<td>39 (59)</td>
<td>17 (82)</td>
</tr>
<tr>
<td>After two months, (n) (% with delirium)</td>
<td>149 (47)</td>
<td>53 (53)</td>
<td>41 (61)</td>
<td>34 (62)</td>
<td>18 (78)</td>
</tr>
<tr>
<td>After six months, (n) (% with delirium)</td>
<td>129 (43)</td>
<td>39 (59)</td>
<td>38 (47)</td>
<td>25 (80)</td>
<td>15 (80)</td>
</tr>
</tbody>
</table>
Ricoeur argues that ‘What has to be interpreted in a text is what it says and what it speaks about’ (Ricoeur 1973b), and in a structural analysis interpretation moves from a superficial to a deeper level. The three levels of interpretation in Ricoeur’s (1973a,b) theory have been operationalised by several nurse investigators (Martinsen & Dreyer 2012, Dreyer & Pedersen 2009, Lindseth 2004). Naïve reading is the first reading of the text as a whole. All interview transcripts were read several times by the investigators before they wrote their immediate first understanding of the text (the text below in the ‘Naïve reading’ section).

The next step was structural analysis on three levels: What is said (quotes), what the text tells us (meaning), and identification of the themes. We structured the quotes in themes with a text explaining the meaning and our interpretation. The interpretation of the findings was further substantiated, by expanding the dialectic movement between explanation and comprehension. Finally, the movement between explanation and comprehension validated the interpretation through argumentation (Ricoeur 1973b). A comprehensive understanding was achieved when the themes were discussed using relevant literature. The investigators negotiated several possible interpretations using impressions from the naïve reading. After several arguments had been unfolded and discussed we decided on the best interpretation (Dreyer & Pedersen 2009). According to Ricoeur, this is referred to as the final act of comprehension leading to a new way of being-in-the-world (Ricoeur 1973b). A new comprehensive understanding of ICU patients’ memories of delusions is reached in the final discussion.

Ethical considerations

The protocol of the main study was approved by the Danish Data Protection Agency and the National Health Service of Denmark. According to the Regional Research Ethics Committee, the present study did not require further approval. The first author obtained consent for participation by the patients when the ICU staff found it ethically feasible. Patients were informed verbally and in writing before consent. The patients were advised of the voluntary nature of the study and their right to withdraw at any time. This was reinforced at each patient contact. Patients were assured anonymity, and all data were handled confidentially by The Danish Data Archive after analysis was finished. During interviews, the order of the questionnaires was not arbitrary, but started with the ICU Memory Tool. At the end of each telephone interview patients were asked if they felt okay, and were offered another telephone call or assistance with contacting their GP if necessary.

Findings

In the following, we present the naïve reading and four themes that emerged from the structural analysis of the
narrative interviews. We have presented our interpretation of the interviews as a whole in four short narratives in Table 2. With these narratives, we attempt to capture the meaning units from all the interview text as told by the 114 participants in a storytelling way as described by Dreyer and Pedersen to illustrate the patients’ feelings and emotions to the reader (Dreyer & Pedersen 2009). In the following, we present an in-depth interpretation of the interviews and substantiate the descriptive themes by quotes.

Naive reading
Naive reading provided the initial spontaneous impression of how patients in our study described their memories of delusions after the ICU stay in their own words. These impressions were expressed as a ‘meaning of the whole’ described in the text below:

The patient memories were diverse and vibrant, including dramatic narratives of journeys, challenges and survival. They described close family members who participated, controlled or observed. The patients took part in scenarios, where they had no influence; close relatives or staff took over and decided the course of events and even patient actions. The patients described how they had to participate in gambling, car races or killings to survive. The patients described different means of moving about, such as hopping, crawling, running, driving, flying or sailing. The vehicles could be the bed, a bus, a racing car, a helicopter or a truck with amphibious ability to drive or cruise under water. Patients experienced transportation from hospital to hospital for continuous treatment. They participated in parties, where the staff brought music and lights, and danced till the break of dawn. Experiences took place in different locations, from Earth to the Moon, or from Heaven to Hell.

Structural analysis
The first impressions in the naïve reading are a Ricoeurian way to ‘unfold in front of the text’ and validate in the structural analysis (Dreyer & Pedersen 2009). Four themes emerged, which are the ever-present family, dynamic spaces, surviving challenges and constant motion.

The ever-present family
It was common for patients to experience their intimates (spouses, children, grandchildren or close friends) as participants in their ICU experiences. Family members invaded scenes where the patient had to choose between life and death – and the family members promoted life. One patient described an experience that follows her to this day:

My worst nightmare was the light at the end of the tunnel: ‘stop breathing and you will get there’. In the other direction was my pregnant daughter was willing me to live. This nightmare has been very disturbing to me ever since. [pt. id 11]

The presence of family members was important, whether alive or dead, illustrating the mixed temporality in many of the accounts. Childhood memories and ICU memories were fused, thus connecting different stages of life and different points in time. In some narratives time moved in reverse as when a patient described a déjà vu experience: ‘It was mostly flashbacks from my life where I got younger and younger’ [pt. id 1006].

Family members could be present in game-like situations, taking control the events: ‘My son and daughter-in-law came up. I was sent to an apartment where they controlled me with a joystick’ [pt. id 505]. Close relatives could also materialise as nurses and participate in daily activities at the hospital. One patient described how the nurses felt familiar: ‘I was visiting some friends. I was lying in the hallway and could see my friends at work, but in reality I saw the nurses’ [pt. id 387]. Close relatives meant a lot because they often sided with the patient in their fight for life; as active or passive observers, the relatives were a part of the patient’s life in the ICU.

Dynamic spaces
Patients recalled rooms and spaces that were not in the ICU. Rooms and content were in constant movement. Patients described ‘white things fluttering about’ [pt. id 1115] or ‘neat small lights revolving about the walls and bean sprouts in a glass of water’ [pt. id 8]. Colours could explode like fireworks or envelope the patient:

It was the colour purple. I couldn’t escape the colour – it pursued me. I was caught by it. I admit that it was hard to describe later – how can a colour go after me? [pt. id 12]

The room, walls, ceiling, windows and interior were elements in strange and vivid ICU experiences. Patients described the experiences:

There were drawings on the walls and the ceilings revolted. The staff laughed and said that it was because I was drugged. Each day there was a new picture on the wall. I felt clearheaded, but one day foxes were running in the ceiling. Another day there was colourful nightclub lighting, especially when I tried to sleep. [pt. id 114]

It was uncomfortable; I didn’t know who I was or where I was. The walls cracked in a spider web pattern and I lost control. The
room was unstable and doors and windows kept moving. [pt. id 180]

The shape of the room and interior confused the patients. Static items started to move and patients felt deceived by their senses as they vividly experienced things that they knew to be impossible. Movement and nebulous items were described: ‘The bed can stand on its end, turn around, or soar toward the ceiling’. Spaces were unstable and unpredictable: ‘I lay in bed and kept sinking – the more I tried to move, the more I sank’ [pt. id 427]. Patients were unable to separate reality and fantasy: ‘It is uncomfortable and makes me insecure; I lose control’.

Surviving challenges

ICU admission was recalled by patients as loss of control when staff or family members took over. Patients participated in games or experiments, where others determined their actions. Patients often experienced conditional situations such as:

I climbed around in the mountains and had to kill a lot of people to return. It felt so real and frightening. I couldn’t get away and I couldn’t find the solution. [pt. id 1151]

In ICU, the experiences felt real, and later on, patients had frightening memories of their fights for survival. Patients recalled conditional games and experiments where they were forced to overcome obstacles or win a battle to survive. Close relatives could be adversaries in deadly games, where the patients had to fight for their lives without assistance. One woman explained how she became suspicious because ‘even the closest family members wanted to hurt me’. Staff members could be involved in games or parties and leave the patients to their fate. One patient said:

The nurses got dressed up and went outside to a large patio, where they danced and partied till five in the morning. There were bed lamps and candy bars on the tables. [pt. id 461]

Patients recalled being forced to accept anything from treatment to liquidation:

I was restrained and forced to be treated. A mask with too much air was forced on me – like holding the head out the car door – panic! The nurse got suspicious because I wasn’t supposed to touch my throat. [pt. id 1159]

The patients felt abandoned when staff members were part of a game where the patient was hurt or killed. One patient recalled: ‘Some of the staff abducted me and tried to kill me. I didn’t think my family knew where I was’.

Experiences were vivid and when patients tried to describe them to their close family they realised after a while that it was ‘only’ a dream.

Constant motion

Patient memories were full of travels and experiences of moving about. One patient stated that he had been in Sweden: ‘There was a helicopter that flew me to Sweden for my surgery’ [pt. id 8]. Patients were in constant motion using vehicles that were anything from their bed to a helicopter:

I sometimes used a truck that drove under water. We also went flying in the same truck … and I ran and ran although I am paralyzed … I jumped off the buildings … drove a bus … and sailed from the hospital. [pt. id 77]

Some patients could state a reason for their journey while others could not. Humans and animals could be involved. One patient had flown off to a party with the Shah of Iran where the toastmaster was unable to speak [pt. id 1013]. Patients experienced travel through time and space and often felt unable to participate or control events. ‘The worst was when someone moved my bed around in my dreams – I have been from Heaven to Hell’ [pt. id 1169].

Discussion

The aim of the study was to describe the content of former ICU patients’ memories of delusions. Our main findings are expressed in the description of four narratives generated from patients’ memories of delusions: the ever-present family, dynamic spaces, surviving challenges and constant motion. Some of the memories make sense in the context of the ICU setting, and others are more unlikely. A secondary finding is that memories of delusions were described somewhat independently of documented ICU delirium.

Some patients had memories of delusions though they never were assessed as delirious while in the ICU (Table 1). There can be several reasons for this: delirium is a fluctuating phenomenon, giving way for episodes of delirium between delirium assessments. Patients in coma cannot be assessed for delirium as they are unable to cooperate during delirium assessment.

Many of the patient experiences described in the study can be justified by actual events and practices in the ICU. Several patients described activities taking place in the ceiling, such as family members hanging from the ceiling or foxes running in the ceiling. This demonstrates the perspective of a patient in bed, providing a full view of the ceiling with limited side vision. One patient experienced being
The patients in our study were asked to recall and describe their memories during the ICU stay, although the memories were potentially unpleasant. We discussed the ethical acceptability of our request, and agreed that many patients were actually relieved and that some had not had the opportunity to tell their story before the interview in our study. The sense of relief has been described in a study as ‘releasing a lot of poisons from my mind’ (Guttormson et al. 2014). Some patients have difficulties coping with their memories (Engstrom et al. 2013), but only two of our participants chose not to describe their delusions. In one study, hallucinations and delusions were described as the most traumatizing aspects of intensive care (Wade et al. 2013), so the importance of verbalising memories can hardly be overestimated. Duppils and Wikblad (2007) found that patients who had experienced ICU delirium eventually became aware that it is a condition that will pass (Duppils & Wikblad 2007). The presence of delirium, however, has not been a reliable method to assess for unreal experiences (Roberts et al. 2006). As such, there is no easy way for nurses to determine which patients might benefit most from telling someone about their experiences.

Unreal experiences in the ICU are often more vivid than ordinary dreams, and they may linger in the patient for years (Roberts et al. 2006, Zetterlund et al. 2012). Patients who state that they have no memory of ICU might have memories of delusions. When these memories are uncovered, nurses can help sort out what actually might have happened. Nurse and patient co-construct a narrative that helps the patient understand what happened in the ICU and connect this to the illness trajectory. Creating an illness narrative potentially aids the process of recovery when events are put into chronological order and dream and reality are separated (Egerod et al. 2011). ICU nurses are in a unique position to help patients make sense of their memories of delusions. Some elements can be recognised and discussed at follow-up consultations or at postrecovery drop-in programs (Svenningsen et al. 2013b).

We did not see any adverse effects associated with our study. Two patients were identified as needing additional counselling and were referred to a physician. One ICU provided follow-up clinic, whereas patients at the other ICUs were referred to their general practitioner if they needed further help.

Strengths and limitations

The narrative interviews were part of a comprehensive structured telephone interview where two open-ended
questions provided the participants the opportunity to narrate their memories of delusions. The study was not planned as in-depth interviews, but trustworthiness was increased by the chosen methodology that enabled us to interpret and critically discuss patient narratives and go from a superficial to an in-depth interpretation. Transparency and credibility were added by adhering to the principles of Ricoeur’s interpretation theory, by substantiating the interpretation with quotes from the narrative interviews. We assume transferability to similar contexts in Danish ICUs as the present study was a multicentre study. Dependability was assured by the use of validated instruments for data generation, and confirmability was ensured by investigator triangulation in the whole research process as the preunderstanding of the three investigators.

Conclusions

Based on 114 patient narratives, we unfolded four basic themes describing memories of delusions in the ICU. Each theme had elements of recognisable facts mixed with delusional experiences. In our sample, memories of delusions were not dependent on the presence of ICU delirium. More studies are needed to understand the meaning of memories of delusions, the commonality of themes, and the association between delusions and delirium after an ICU stay.

Relevance to clinical practice

We recommend ICU follow-up that enables patients to describe experiences including feelings of harm, nightmares or hallucinations in the ICU. When patient narratives are described, ICU nurses might be able to help the patient sort out what was real and what was fantasy as a step towards patient recovery.

Disclosure

The authors meet the criteria for authorship as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content and (3) final approval of the version to be published.

Conflict of interest

The authors have no conflicts of interest to report.

References


