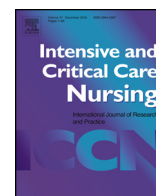




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The contents of a patient diary and its significance for persons cared for in an ICU: A qualitative study

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ABSTRACT

Objectives: The aim of this study was to describe the contents of a patient diary and its significance for persons cared for in an ICU.

Research Methodology: An empirical study with a qualitative design. Eight telephone interviews and one face-to-face interview were conducted with nine persons previously been treated in an ICU and been given a patient diary. In addition, the person would have read his/her diary. The data have been analysed with qualitative content analysis.

Findings: The study identified one overarching theme; Gaining understanding, and four categories; The diary is written for me, Creating memories from the time of care, Who writes in the diary and, The ability to return to the diary. The diary meant that participants gained an understanding of their time in the ICU while they were critically ill and the diary was important to be able to return to.

Conclusion: What formerly critically ill patients appreciate most about the diary is that the diary is personally written, which makes them feel confirmed and valuable as a person. Guidelines for how and when a diary should be written and used would likely encourage critical care nurses and relatives to write in it.

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Implications for clinical practice

- Patients feel cared for when they read a diary written especially for them.
- Guidelines outlining what should be in a diary would encourage critical care nurses and relatives to write and place photos in it.
- Critical care nurses allocating time daily to write in the diary will reduce gaps in the diary, thereby preventing patients from wondering what happened during that time.

Background

Any person who is critically ill and is being cared for in an intensive care unit (ICU) is in an extremely stressful environment and situation. According to several studies (Ullman et al., 2015; Ewens et al., 2014; Bäckman et al., 2010), those who have been nursed in an ICU for critical illness have an increased morbidity. When the person recovers, they often experience a state of confusion or suffers from memory loss. An ICU patient diary has been found beneficial in reducing ICU patients' and their relatives' suffering (Teece and Baker, 2017; Nydahl et al., 2014; Jones et al., 2012). According to

Nikayin et al. (2016) one third of patients who survived their ICU experienced anxiety during the first year of recovery; they suggest physical rehabilitation and ICU diaries merit further investigation as interventions.

According to Engström et al. (2009), a patient diary can help a person who has been cared for in an ICU to understand what they have undergone; the diary can thus assist the person to experience a sense of coherence (Engström et al., 2009; Engström et al., in press). Studies show that the diaries make it possible for the person treated in the ICU to confirm his/her memories and fill in memory slots (Ewens et al., 2014; Engström et al., 2008; Taylor et al., 2017). Heindl et al. (2016) show that implementing and developing a nursing intervention such as the ICU diary demands a process of continuing adaptation. According to Åkerman et al. (2010), the inspiration to write a diary increases when colleagues are discussing the impor-

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tance of the diaries. In order to facilitate the recovery of people who have received a diary, we need to understand which contents of the diary will likely be significant for them. This study focuses on what contents in the diary are helpful to the patient.

Aim

The aim of this study was to describe the contents of a patient diary and its significance for persons cared for in an ICU. The study answered the following research questions:

1. Is there anything in the content to focus more on?
2. What is important to read about and who should write in the diary?
3. Is there something that the person who has been cared for in the ICU thinks that staff and/or relatives should avoid writing in the diary?
4. How has the diary been used?

Method

Design

The study used an empirical qualitative design (Polit and Beck, 2016). During February–March 2017, eight telephone interviews and one face-to-face interview were conducted. Data were analysed using qualitative content analysis as described by Graneheim and Lundman (2004).

Participants and procedure

Participants were included in the study: 1) if they were over 18 years 2) had previously been treated in an ICU for at least 72 hours, and 3) had read their diary. Participants were selected by a contact critical care nurse (CCN) at the ICU who is responsible for following up with previous intensive care patients. She received information about the aim and method of the study, and then communicated with those who met the inclusion criteria and asked if they were interested in participating in the study. Prospective participants received oral information about the aim of the study and what taking part in it would entail. They were also informed that they could change their minds at any time.

Context

The study took place in a general ICU in the northern part of Sweden. The ICU has six beds and about 15 postoperative beds. Patients in the ICU are hospitalised for a variety of medical and surgical diagnoses, including sepsis and trauma.

Data collection

Semi-structured qualitative telephone interviews were conducted by the first two authors (Table 1). To confirm that the questions addressed the aim of the study, a pilot interview was conducted. The interview guide was developed with help of previous studies (Ednell et al., 2017; Engström et al., 2009). The pilot interview was conducted under the same premises as the other interviews, except that it was conducted face-to-face. Since the pilot interview answered the aim and contained useful content, the authors chose to include this interview in the study. The first author conducted four interviews and the second author conducted five interviews, each one taking between 30 and 60 minutes. The interviews were recorded, after which they were transcribed on password-protected computers.

Table 1
Interview Guide.

Please tell us what happened. Why were you in the ICU?
How do you feel today? How is your physical condition? Can you tell me about your mental mood?
Can you tell me if you have any memories of your time in the ICU? Dreams? Nightmares? (Usually during and after the event)
Can you tell us something you thought about in reality? Can you tell me if there is something confirmed in your diary?
When did you get your diary?
When was the first time you read it?
How did it feel?
How many pages did you read?
How many times have you read it? When did you read it the most?
How would you describe the contents of your diary? Pictures? Concrete descriptions of your care, like examinations or operations, etc. or ...?
Who has written in your diary (CCNs? Other staff? Relatives?)?
Can you describe how it felt like reading it?
Is there anything that you remember or wonder about which the diary helped you with?
Any content or any pages that were particularly significant?
Any content or pages that concern you emotionally?
Was there anything missing from the content?
Was there anything special that you wanted to have written in it?
Do you feel that the diary made you feel more involved in the care process?
If yes, under what conditions?
How would you like it to be designed to help you more?
Was there anything in the content that you did not want to read?
Have you visited the ICU since you were discharged? Did you go through the contents of the diary then?
Is there anything more you want to add about the content of your diary that we haven't mentioned yet?
Supplementary questions:
Can you tell me more?
Can you clarify?
In what way?
Why do you think you feel so?

Ethical considerations

The University Ethics Committee approved the study (LTU-781-2017). Informational letters and a written request to carry out the study were sent to the ICU medical director at a hospital in northern Sweden. After receiving written approval for the study, participants were contacted in writing. All participants verified their participation by filling in and returning a reply to the authors; the reply slip was included with the information letter. As each interview began, the authors checked that the participant understood the aim of the study by going over the information letter. They were also informed that they could cancel their participation at any time and that their decisions would not affect their care. The participants were guaranteed confidentiality in the presentation of the findings.

Data analysis

Demographic data included age and length of ICU stay was describing using median (Mdn) and range. Qualitative content analysis was conducted of the interviews following Graneheim and Lundman (2004) and Graneheim et al. (2017). The analysis was conducted by the authors reading the collected material in its entirety repeatedly. This created a “feeling” for the collected material. Based on the aim of the study, “meaning units” were extracted from the material along with surrounding text to ensure each meaning unit could provide understandable context. In total, 178 meaning units consisting of sentences and phrases addressing the aim of the study were identified. The meaning units were then condensed to retain the essence of the text without changing or reinterpreting the content. The next step, categorisation, took place in three

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