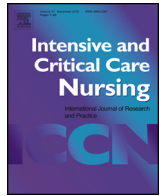




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Original article

The meaning of personal diaries to children and families in the paediatric intensive care unit: A qualitative study

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ABSTRACT

Objective: To explore children's and families' experiences of using intensive care diaries after discharge and the role of diaries in the process of recovering from a stay in the paediatric intensive care unit.

Design and setting: Qualitative, exploratory design. Data collection consisted of semi-structured interviews with five children and their families, conducted four to six months after discharge from the intensive care unit. Inclusion criteria were children and their families, with a stay for more than three days who had a diary written for them. Data were analysed using thematic analysis

Findings: Three main themes emerged: (i) value to the entire family, (ii) creating memories, (iii) the importance of pictures.

Conclusion: Diaries were used after discharge as a support for both children and families and played a role in making the paediatric intensive care experience meaningful by providing explanations and coherence. The findings suggest that a diary can serve as a catalyst for the coping process of the family unit. Findings also confirm how the children's memories are characterised by a sense of unreality. The diary could thus help fill in some of the missing picture to support the children in understanding their story.

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Implications for clinical practice

- Personalised diaries written by nurses during a child's stay in the paediatric intensive care unit can be supportive to the child and family after discharge, by providing explanations and filling out some of the missing picture.
- Entries should be age-appropriate and descriptive. When describing the child's reactions to events, it is important to leave room for the child's own interpretation.
- The diary should contain pictures of the child as a patient in the intensive care surroundings.

Background

Our knowledge about the psychosocial outcomes for children following stays in intensive care units (ICU) is growing (Rennick et al., 2014). Several negative outcomes have been identified, such as anxiety, fear, behavioural changes, elevated levels of post-traumatic stress disorder (PTSD) and reduced health-related quality of life (HRQOL) (Colville, 2008; Colville and Pierce, 2013; Rennick and Rashotte, 2009). Such results have prompted increased

focus on the need for after-care measures and interventions to prevent negative outcomes for children.

This development sees a parallel in adult ICUs, where one such intervention is the writing by nurses of personalised diaries for the patient. Diaries are presumed to aid patients' recovery by filling memory gaps, and providing explanations to achieve a coherence and understanding of their experiences (Ewens et al., 2015). Research involving adult ICU survivors suggests a positive effect on PTSD symptoms, and on anxiety, depression and quality of life (Backman et al., 2010; Ewens et al., 2015; Garrouste-Orgeas et al., 2012; Jones et al., 2010; Knowles and Tarrier, 2009). Although a systematic review has found inadequate evidence from randomised controlled trials to support the effectiveness of diaries (Ullman

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et al., 2014), the practice seems to be spreading in Scandinavian and other Western countries, as part of follow-up programs for ICU survivors (Egerod et al., 2011; Heindl et al., 2016; Nair et al., 2015; Nydahl et al., 2010).

There is a lack of knowledge, however, about the extent to which ICU diaries are being applied in paediatric intensive care units (PICU) and there are no studies on the effect. The use of retrospectively constructed storybooks as part of a follow-up service has been reported from one center (Colville, 2008).

The writing of diaries for children differs in several ways from those for adults. The PICU population is heterogenic in age and development and requires specific attention to language and content in a diary. Although the principal target group for the intervention is the children, parents are involved in giving consent, as readers and sometimes as contributors to the diary. The therapeutic intervention is thus aimed at both the child and the family.

To date, there have been no reports on the use of PICU diaries and we have no knowledge about how families use the diary after discharge from a PICU unit, or whether it has a role to play in the family recovery process. Thus, the purpose of this study was to explore the meaning of PICU diaries to children and their families, as reported in their own words.

Method

Objective

The study aimed to explore children's and families' experiences of using intensive care diaries after discharge and the role of diaries in the process of recovering from a stay in PICU

Setting

The study was conducted in a tertiary hospital setting within a six bed, multidisciplinary unit, at which children of all age groups, including neonates, were received. The majority were children of under two years of age. All medical and surgical specialties, apart from heart surgery, were represented. The mean length of stay in the unit was 2.6 days (2016).

The unit was selected for the study, because for the past 10 years, the nurses have been writing personal diaries for children admitted for three days or longer.

The diary consists of daily records written by the nurses, supplemented by pictures of the child and family, as well as pre-prepared pictures and texts explaining certain procedures and equipment, selected for the individual child according to relevance. All content is placed in an A5 binder, in which an introduction page provides information about the purpose of the diary. The parents, and if possible, the child are also informed verbally by the nursing staff and their consent is requested. Parents do generally not write entries but are encouraged to write their own diary and some write letters addressed to the child. The diary is kept at the bedside and handed over to the child and family on the day of discharge from the PICU.

Study design and recruitment

The study had a qualitative, exploratory design in order to capture and understand the experiences of the participants from their perspective (Parahoo, 2014). Data collection consisted of semi-structured interviews with the child and family, conducted four to six months after discharge from PICU.

Inclusion: children, and their families, with a PICU stay for more than three days who had a diary written for them. The three day limit was chosen because this is the minimum stay required before a diary is started. Because the intention was to gather informa-

Table 1
Participant characteristics.

Patient no.	Child gender	Child age	Days of admission	Family participating
1	F	11	12	Mother, sister
2	M	5	38	Mother
3	F	10	3	Mother
4	F	7	5	Mother, father, sister
5	F	14	5	Mother, father, sister

tion about the experiences of the children as reported in their own words, the minimum age criterion was set at four years of age.

Exclusion: non-Danish-speaking families.

Sampling was consecutive over a six-month period in 2011.

The families were approached shortly before or following discharge from PICU to ask for permission to contact them after hospital discharge with an offer to participate in the study. If consent was given, the family received an invitation letter including a plain-language description of the protocol and a consent form to be signed by the parents and returned.

In the invitation letter, the term "family" was used rather than parents or mother/father, because this allowed for the families to decide for themselves who should be present at the interview, according to their own definition of the term.

The families were offered a choice of location for the interview – either at home or at the hospital.

Participants

During the six-month period, all families who fulfilled the inclusion criteria were recruited, giving an initial sample of seven children from six families. One family declined participation at the second approach, and one never responded to the invitation letter.

The included participants were thus five children (two of whom were siblings) and their families; aged 5–14 years (mean 9.4). Length of PICU admission was 3–38 days (mean 12.6).

The characteristics of the participants are presented in Table 1.

Ethical considerations

The study was approved by the management of the department and written consent was obtained from the adult participants, thus complying with Danish legal requirements.

All data were kept confidential and only the researchers and secretary had access to the original interviews.

In the invitation letter to the families, it was specifically stated that participation was voluntary and that consent could be withdrawn at any time. It was explained that data would be anonymised before any publication. In the article, the children are characterised only by age, gender and length of stay; references to any medical history are not included in the quotations.

Data collection

The interviews took place at the families' homes (three) or at the hospital (two), with both researchers present.

The two researchers were experienced paediatric critical care nurses, trained in communication skills and used to handling parents and children in emotional distress. Both worked in the unit and either one or both of them had met the families during the admission, thus a relationship had been established prior to the interviews.

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