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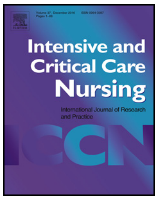

Parents' experiences and the effect on the family two years after their child was admitted to a PICU—An interview study

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ABSTRACT

Background: For parents, having a child admitted to a paediatric intensive care unit (PICU) is a very stressful experience filled with anxiety. Parents are often scared and traumatised. This stress can lead to PTSD.
Aim: The aim was to describe parents' experiences and the effect on the family two years after their child was admitted to a paediatric intensive care unit.
Material and methods: Ten parents were interviewed according to a semi-structured interview guide. An inductive approach was applied for the study and qualitative content analysis was used to analyse the data.
Findings: The parents carried vivid memories and they were still strongly affected by the experience of having their child admitted to a paediatric intensive care unit. They could clearly recall the environment, feelings that affected them and how they felt powerless. The relationship between the parents had been strengthened.
Conclusion: Parents, siblings and the ill child could all show symptoms of anxiety, stress and sleeping disorders. The parents valued life differently.

Implications for clinical practice

- This study concludes that it is important to try to involve the parents in the care of the child as well as preserving the family's privacy, the parents relationship and bonding to the child treated at the PICU.
- The study also showed that it was important to have support from the health care staff and relatives.
- The result of this study could be used as basis to the care in the PICU as well as a follow-up service for the children and their families after the PICU care.

Introduction

For parents having their child admitted to a paediatric intensive care unit (PICU) is a very stressful experience filled with anxiety. Parents are often scared and traumatised and carry a constant fear (Colville and Gracey, 2006; Svavarsdottir and McCubbin, 1996). They also experienced feelings of unreality and vulnerability in the situation. Some parents could not recognise their child because of the changed behaviour and the appearance of an anaesthetised condition and oedema (Colville et al., 2009; Latour et al., 2011). Furthermore, the parents describe the environment in the PICU as generally shocking.

The fear and anxiety lead to stress, which in some cases remained for as long as six months after the child had been discharged from the PICU. Recalling painful examinations and treatments such as blood sampling, suction of the airways and intubation performed on the child increased the parent's anxiety. Also recognising sounds, people or environments connected to the PICU brought distressing memories back (Board and Ryan-Wenger, 2003).

Fear and stress can lead to the development of acute stress disorder (ASD) as well as post-traumatic stress disorder (PTSD). To prevent parents from developing ASD and PTSD the PICU team

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needs to be aware of the risks (Bronner et al., 2008; Bronner et al., 2010). Acute stress disorder (ASD) is a marker for developing PTSD. It has been proven that infants whose parents suffer from PTSD have a greater risk of developing sleeping and eating problems (Balluffi et al., 2004; Shaw et al., 2009).

Parents who participated in follow-up appointments two months after their child was discharged from the PICU revealed lower stress factors. During these appointments it was verified that the parents wanted to discuss the care to clarify information during the hospitalisation and reflect on situations that had affected them emotionally (Colville et al., 2010). Therefore, it is most important to give follow-up care and attend to the needs of parents who have had a child admitted to PICU (Bronner et al., 2008; Bronner et al., 2010). Furthermore, information about prognosis and treatment limits anxiety and depression among close relatives of patients treated at PICU (Rusinova et al., 2014).

Anxiety and symptoms of ASD are more often present in family members when the patient/child is in lower teens and younger (Mortensen et al., 2014; Rusinova et al., 2014). To practice family-centred care (FCC) when children are treated in hospitals reduces the parents stress (Mortensen et al., 2014). To illuminate the comprehensive knowledge of what constitutes FCC, Mikkelsen and Frederiksen (2011) raised the main themes which are:

- good relationship between the professionals and the families
- shared responsibility and taking part in decisions
- allowing the family to keep its autonomy over the child
- providing assistance as professionals during the child's care
- giving the family the support that is needed.

Several studies, for example Balluffi et al. (2004), Colville and Gracey (2006), Latour et al. (2011) have focused on parents' and caregivers experience of having their child admitted to a PICU or neonatal intensive-care department. The difference in our study was that we wanted to explore how parents experience their child's admission to PICU as well as what memories they carried with them two years after and how it has affected the families. Many previous studies on parental experiences of PICU have used a quantitative approach such as Board and Ryan-Wenger (2002), Davidson et al. (2012); Bronner et al. (2010), to reach a deeper understanding a qualitative approach has been used in this study. Furthermore, the aim was to describe parents' experiences and the effect on the family two years after their child was admitted to a PICU.

Method

Design

A qualitative method with semi-structured interviews was used for this study which was suitable to describe parents experience of having their child admitted to PICU. Qualitative content analysis with an inductive approach was employed to analyse the data according to Graneheim and Lundman (2004a).

Setting and participants

In Sweden there are four paediatric intensive care units (PICU). The PICU where the study took place is an eight bed unit which cares for children from birth (full-term) to the age of 18, and advanced care is given in a high-tech environment. The PICU unit treats and cares for children with congenital heart disease, complex surgical deformities, sepsis, cancer, trauma and medical state who are in need of intensive care and monitoring. The unit runs a national programme for children with congenital heart diseases. The total admission is about 500 ICU admissions/year.

Ten parents whose children were admitted to a PICU in Sweden between November 2012 to December 2013 were interviewed. In families with two parents both were asked to participate. Eight parents who been interviewed were couples and two parents were out of separate families. All of the children that participated in the study suffered from severe congenital heart defect (CHD).

Inclusion criteria

- Parents whose child had been admitted to PICU for at least one week, (the range was days to 18 days, with a median of 10 days).
- Age of the child should be 0–5 years.
- The parents had to be able to speak and understand Swedish.
- Two years had to elapsed since the child was discharged from the PICU the range was 2–2,5 years.

Exclusion criteria

- That the child had died after discharge.

Ethical approval

The parents were informed by a contact nurse and provided with written information about the purpose and implementation of the study. Participation was voluntary and the parents were told that they could withdraw without giving any reason. Written informed consent was obtained from the parents who agreed to participate in the study. The interview material was encoded to ensure the confidentiality of the parents. As there was a risk that the parents, in connection with the interview, could relive stressful events that occurred during the hospital, a counsellor or psychologist was on hand if mental stress reactions should occur. Ethical permission to carry out the study was approved by the regional board in Lund; DNR.2013/739.

Data collection

A contact nurse at the paediatric unit made a selection among the children based on established criteria. The families were asked two years after discharge from the PICU (April 2015 to January 2016) if they agreed to participate in the study. Thereafter the authors contacted the parents who had agreed to participate by telephone or email, to schedule an interview. The study was conducted from April 2015 to August 2016. The second author has long experience of PICU, NICU and experience from research in nursing, the first author has experience of working with children in emergency care. After they had given their consent, the researcher contacted them to give further information and schedule a time and place for the interview. Fourteen parents were asked by the contact nurse, the researcher contacted them all by email to schedule an interview; ten parents responded. Written consent to participate was collected at the time of the interview. The participants could choose if they wanted to meet in person for the interview or whether it would be done by telephone. The interviews were recorded and then transcribed verbatim. Two parents chose to meet in person in their home for the interviews. The rest of the interviews were conducted by telephone. In addition to the ten interviews two pilot interviews were performed; these were excluded from the study, as the child in the pilot interviews was hospitalised for only two days. The interview guide was constructed based on the literature research and the co-author's experience as intensive care nurse. The aim of the pilot interviews was to adjust the interview guide to ensure that the issues responded to the study's purpose, which led to some adjustments of the interview guide. The interview followed a semi-structured interview guide presented in Table 1.

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