PARENTS’ EXPERIENCES OF THEIR CHILD’S ADMISSION TO PAEDIATRIC INTENSIVE CARE

Ruth Oxley analyses how parents have coped with witnessing their child’s passage through intensive care

Abstract

**Background** Admission of a child to the paediatric intensive care unit (PICU) may be one of the most stressful events for parents because the outcome is often uncertain. So how do parents cope, and how can we as nurses help them?

**Aim** To explore the lived experiences of parents whose children have been admitted to a PICU.

**Methods** Using Heidegger’s school of interpretative phenomenology, six unstructured interviews were conducted. These were transcribed and analysed following interpretative phenomenological analysis. Participants were chosen through purposive sampling.

**Findings** Each participant had different emergent themes. Themes included trauma, responsibility, anxiety about where the child is, post-traumatic stress symptoms and transfer to the ward.

**Conclusion** The lived experience of a parent is fraught with varying different emotions, with the beginning of the journey and the ending of the PICU admission causing the most anxiety.

**Keywords** Child health, children’s nursing, family-centred care, intensive care, parents

INTENSIVE CARE units (ICUs) are one of the most complex and stressful departments in medicine (Bennun 1999). They represent the amalgamation of a range of clinical presentations and therefore different specialties and expertise.

The databases Cumulative Index to Nursing and Allied Health Literature, PsycINFO, Medline and the Cochrane Library were searched between 2009/11, with the following terms: paediatric/pediatric intensive care, parents/mothers/fathers, children, experiences and effects/coping/stress/post-traumatic stress (PTS). While children were not the primary focus of this study, it is important to note that admission to a paediatric intensive care unit (PICU) can leave a child traumatised (Ehrlich et al 2005, Ward-Begnoche 2007, Bronner et al 2008b, Colville 2008).

Studies (Diaz-Caneja et al 2005, Ehrlich et al 2005, Bronner et al 2008a, Colville et al 2009) show that parents with children in PICU find the experience stressful and may suffer for many months after discharge due to the traumatic nature of intensive care. Colville et al (2009) emphasise that the removal of all stress from parents in this situation is an unattainable aim, but there may still be things that can be changed to make the journey less traumatic.

Bronner et al (2008a) studied the prevalence of PTS in parents after an admission to PICU and more than three quarters of their sample (247) experienced persistent symptoms of PTS disorder. Colville et al (2009) concluded, through the use of semi-structured interviews with 32 mothers and 18 fathers, that parents suffered...
The parents of a child admitted to paediatric ICU experience most anxiety at the beginning of the journey and at the end of the admission.
persistent and significant distress after discharge, but further research is needed into how best to support parents.

Family-centred care is a philosophy that steers practitioners away from paternalistic approaches in their delivery of care toward partnership with families (Cushing 2005). It is the parent, not the healthcare provider who is continuously present in the child’s life and will be ultimately responsible for their child’s health and wellbeing.

It is the responsibility of nurses and other healthcare professionals to support and encourage parents in continuing this vital role. When a child is suddenly admitted to PICU, parents experience stress, anxiety and role confusion. Study et al (2006) in their systematic literature review on the impact of paediatric critical illness on families demonstrate that one of the most common stressors for parents is alteration to the parental role. In PICU, the hospitalised child demands complex medical care that the parents are unable to provide.

The research shows that a PICU admission is stressful, with long-lasting effects on the child and the parents. It is suggested that, if a parent’s experience of their journey on PICU can be understood, it may be possible to reduce the trauma that they experience. Minimising the stress on parents will hopefully reduce some negative effects the admission may have had on their child. Nurses must accept the responsibility of being active in providing high quality care to their clients (Cannon and Boswell 2011), which is based on the most current information possible.

**Box 1 Inclusion criteria**

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<thead>
<tr>
<th>Criteria</th>
<th>Rationale</th>
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<tr>
<td>Emergency admission</td>
<td>Planned admissions are prepared for the paediatric intensive care unit (PICU), which involves a visit to the unit and meeting staff, whereas with an emergency admission there would not have been time to prepare the parents</td>
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<tr>
<td>First admission</td>
<td>If child had been admitted to PICU before, then family would know what to expect</td>
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<tr>
<td>Child must not have been looked after by the researcher</td>
<td>The researcher must be independent of the PICU team to limit the Hawthorne effect (Adair 1984), which suggests that people modify their behaviours and responses because they are being observed. In health-related research, if the researcher is part of the care team, participants may think that they have to say certain things because their comments may affect the care provided</td>
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**Aim**

The aim of this research was to explore the lived experience of parents whose children have been admitted to a PICU and to illuminate potential changes that could help parents in the future.

**Methods**

Phenomenological research is a qualitative research method that allows for examination of the meaning, exploration, description and understanding of human experience (Munhall 1994, Caelli 2000); the overall purpose is to provide answers to important questions and deep human concerns by interviewing the people concerned (Cohen and Omery 1994).

Phenomenology is fundamentally a philosophy with both epistemological and ontological branches (Mackey 2005). Edmund Husserl (1859-1939), a German philosopher and mathematician, operated from an epistemological stance (Mackey 2005), aiming to describe how the world is constituted and experienced through consciousness. Heidegger (1889-1976), a student of Husserl, sought to answer the question of being, operating from an ontological stance. Heidegger examined hermeneutic or interpretative phenomenology: all experiences are mediated by interpretation and understanding involving an exploration of language.

Hermeneutic – a Greek word meaning ‘to interpret or translate’ (Dombro 2007) – phenomenology is both descriptive and interpretive. Its purpose is to give a voice to human experience just as it is (Jardine 1990). Knowledge, resulting from phenomenological inquiry, becomes practically relevant in its possibilities of changing the manner in which a professional communicates with and acts towards an individual in the next situation they encounter. This research was based on Heidegger’s phenomenology.

**Participants** Purposive sampling was used to identify participants. The study took place in a 13-bed regional PICU. Purposive sampling allows participants to be chosen because they have knowledge and experience of the subject being researched. However, this does not provide a simple approval to any potential participant. It demands that we think critically about the parameters of the population we are interested in and choose our sample carefully (Silverman 2010).

The sample was identified by the researcher, using the inclusion criteria set out in Box 1. Nine participant packs were sent out at the end of June 2011, with three responses. A further five packs were sent out in July, eliciting another three responses. The respondents were then contacted by the researcher through their preferred method of contact. The final sample consisted of
five mothers, and one couple, who were counted as one participant because the father was not present for the whole of the interview.

**Data collection** Five unstructured interviews took place at the participants’ home, and one on the children’s ward. All interviews took place between July and September 2011 and lasted 30-90 minutes. Participants signed a consent form before the interview, which started with the researcher inviting the interviewee to explain how they came to be on PICU. The purpose of unstructured interviews is to allow the participant to tell their story with as little direction from the researcher as possible. Interviews were audio-recorded.

A reflective diary – following Johns’ (1995) reflective cycle – was completed immediately after the interview. It is recommended that researchers write a reflexive journal (Koch 1996), in which they describe and interpret their experiences. A journal will counteract assumptions being made by researchers due to their biases, stereotypes and prejudices (Munhall 2007).

**Data analysis** The interviews were transcribed by the researcher. When researching analysis tools for phenomenological research, it became obvious that descriptive analysis is popular. However, this research project focused on interpretative phenomenology, following Heidegger. Therefore, descriptive analysis – which follows Husserl – was not appropriate.

It was, therefore, decided to use interpretative phenomenological analysis (IPA) (Smith et al 2009). The primary concern of IPA is the lived experience of the participant and the meaning that the participant takes from that experience. Once all interviews had been transcribed, they were analysed individually using IPA principles for analysing transcripts (Box 2).

**Ethical considerations** Approval for this study was obtained from the South Central Strategic Health Authority ethics committee and the local NHS trust research and development department. The PICU psychologist was also aware of the study in case any participants needed support as a result of retelling their story.

**Findings**

The themes emerged from the descriptive comments, the linguistic comments and concepts. The common emergent themes between the participants are listed in Box 3.

**Post-traumatic stress syndrome** Four out of the six participants were experiencing symptoms of PTS, with heightened anxiety, nightmares and flashbacks, for example, ‘I can talk about it better now… as you can see, I still get upset by it… I try not to think about it too much… there’s a lot of things I can’t face since it’s happened’ (participant A).

The participants were interviewed up to a year after hospital discharge. One of them was about to begin counselling at the time of the interview, and another sought help after the interview. Four of the six thought that they had changed the way they parented due to their child’s PICU admission, with three becoming more protective. One commented: ‘When she got home, I was so protective I didn’t want to go out to anyone’s house I didn’t know… overly well – just in case it wasn’t clean and she picked something up’ (participant B).

Participant E however became more awake to enjoying her child: ‘He had a whole list of things he wanted to do before we’d started the summer holidays, and I think that just made me more conscious to make sure we did them… this is your list… and we did them all… It was so important to watch him enjoy those…’

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**Box 2** Interpretative phenomenological analysis steps

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<tr>
<th>Step</th>
<th>Reasoning</th>
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<tr>
<td>Reading and re-reading</td>
<td>□ Immersing oneself in the data  □ Listening to the audio recording while reading it</td>
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<tr>
<td>Initial noting</td>
<td>□ The most detailed and time consuming, examining semantic content and language  □ There are no rules or requirements about what is commented on  □ Broken down into descriptive, linguistic and conceptual</td>
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<tr>
<td>Developing emergent themes</td>
<td>□ This involves the first stage of the hermeneutic circle because parts of data will be analysed separately from the whole interview but still within the context of the whole</td>
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<tr>
<td>Searching for connections across emergent themes</td>
<td>□ Mapping out how the themes fit together</td>
</tr>
<tr>
<td>Moving on to next case</td>
<td>□ The next case starts from the beginning as a completely new case</td>
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<tr>
<td>Looking for patterns across the cases</td>
<td>□ Are there any patterns across all the cases?</td>
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**Box 3** Common emergent themes

- Post-traumatic stress symptoms
- Communication
- Not my boy
- Cannot leave
- Too much pressure
- Nightmare
Communication  None of the participants faulted any of the staff from the emergency services and PICU. However, lack of communication increased parents’ anxiety levels. ‘A few times when something would go off or they would rush over to change things... it would only be things like medication... I just thought, “oh, my god, what’s going on” and then afterwards they said, “oh, we’ve just done this...”’ I know they were just doing their jobs, and if it had to be done it had to be done – no explanation beforehand... That’s fine, but it freaked me out a bit at times’ (participant F).

Due to the one-to-one nursing ratio in PICU and doctors always being present, parents found information easier to access in PICU compared with the ward. ‘In PICU, there was a lot of information... if I wanted to know what they were doing, someone told me. If I wanted to know when the doctor was next supposed to come round, someone knew... Then up on G ward, if you had a question... honestly... first, you had to find someone to ask, usually that person couldn’t answer your question and had to get back to you, and then they had to remember to get back to you’ (participant B).

The experience the participants had on the children’s wards once their child had been discharged from PICU were different, with four of the six finding it more difficult than the preceding discharge from PICU. ‘The intensive care... as I say, was fantastic... with high dependency – fantastic... but being on the wards is like being out on the streets...’ (participant D).

Not my boy  Four out of the six did not believe or recognise their child. Participant C only recognised her child once the child had been intubated, due to the severity of the increased work of breathing. The other three participants did not recognise their child due to the intubation and the sedation. ‘For him to be lying sort of straight flat on his back, hands by his side, so unnatural, he’s never been like that in life, so... it didn’t look like him and it didn’t feel like him...’ (participant E).

Cannot leave  Like the communication theme, this theme was relevant to both PICU and the ward. Participant B did not like leaving her child alone on PICU, she felt more reassured if there was always a relative at the bedside just in case her daughter woke. Three participants said they could not leave their child once they were on the ward because there was no one to watch them while they away.

Too much pressure  Three of the six thought that, once on the ward, all the responsibility to look after their child was on them, and this was too much. ‘There were times when I felt like I was starting to become a pain... and I remember feeling really helpless, because all I knew was that my son had nearly died a week ago... the responsibility of making sure that he was alright I found really difficult...’ (participant A).

It is almost as if they lost confidence in their ability to parent and needed this built back up again, especially because they were terrified of their child becoming sick and being admitted to PICU again.

Nightmare  Five of the six described the experience as one of the most frightening things they had ever had to face, using words such as ‘horrendous’, ‘devastated’, ‘helpless’, ‘petrified’, ‘nightmare’. However, because participant C was a healthcare professional, she was much more at ease in the hospital environment than the other participants.

Discussion  The main aim of the research was to see how parents cope with their child’s admission to PICU. Through the analysis it is evident that they all lived minute by minute through their child’s admission. Their journey was traumatic, emotional and devastating. It seems that they ‘cope’ while they are in hospital, but, once at home, it takes some time for the reality of what has happened to sink in, and this is the time when they get flashbacks and would rather forget the event ever happened.

All participants were asked whether they thought there was anything that staff could do in PICU to improve their experience. All six said no. However, analysis shows that there are things that added to their stress. Four of the six parents found the transfer to the children’s ward traumatic. They felt that, considering they had just witnessed their child almost die, there was too much responsibility on them when they transferred to the ward. They needed reassurance that they could ‘parent’ again, and that their child was stable and safe.

Part of the nurse’s role is to break down barriers to ensure that the parent-child bond is nurtured and supported, despite undergoing a frightening experience (Stevens 2004). Four of the six felt isolated on the ward and struggled to obtain information about their child’s care, in comparison with the one-to-one care they received on PICU. Five of the six struggled to come to terms with their child’s admission and, subsequently, had flashbacks.

Limitations and strengths  This study looked at a very small, select sample, so it is not appropriate to generalise the findings of this study. A further
consideration is the possibility that, because participants knew that the researcher was a PICU nurse, but had not been involved in their child’s care, this influenced their ability to be completely open about their time on PICU and, subsequently, the possibility for change.

It is also important to note that no single parent’s journey is the same. Therefore, nurses need to be sensitive to each family they care for, responding appropriately to each one’s coping mechanism. That an individual’s experience can be explored is a strength of this research and of qualitative research in general.

Conclusion
The lived experience of a parent through their child’s admission to PICU is fraught with a range of emotions, with the beginning of the journey (the child deteriorating) and the ending of the PICU admission (transfer to ward) causing the greatest anxieties. The emotional trauma of admission to PICU does not end when the child is discharged from PICU, but continues for months afterwards. While it would be impossible to take away all the emotions connected with potentially losing a child, it has been indicated that things such as good communication and positive transfers to the ward would make the whole journey less traumatic for parents.

Implications for practice
- Transfer to ward is a significant cause of stress
- Information and communication help reduce parental anxiety
- Parents may have lost confidence in their parenting skills following their child’s acute admission to a paediatric intensive care unit (PICU)
- Parents may experience post-traumatic stress syndrome following a PICU admission and may need support

References