

## The Impact of Observed Trauma on Parents in a Pediatric Intensive Care Unit

“Can I see another's woe, and not be in sorrow too?” (William Blake):

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## **Abstract**

Objective: To explore parents' experiences of "observed trauma," defined as traumatic events, unrelated to their own child, that parents/ carers witness while in a Pediatric intensive care unit (PICU).

Design: Exploratory qualitative study.

Setting: Nineteen-bed mixed surgical/medical PICU in a tertiary university-affiliated children's hospital.

Participants: Parents of 11 children, screened from a total sample of 100 children admitted to the PICU for >48 hours.

Interventions: Face-to-face screening interviews were conducted with parents following their child's discharge from PICU. Parents who reported observed trauma were interviewed a second time to explore their experiences.

Measurements: Two questionnaires were designed, one to screen for observed trauma and a second one to guide semi-structured interviews.

Results: Of 100 parents who participated in a structured screening interview, 19 % reported observed trauma. Of the 19 parents, 11 completed the second interview. Significant themes included: involuntary exposure; privacy and confidentiality; empathy for children and their families; reflection and personal growth and staff communication.

Conclusions: Observed trauma is not uncommon in the PICU. The results suggest that timely support may alleviate the short-term negative impact. Furthermore, some parents have reported positive aspects to their experience.

## **Introduction**

Parental stress in the Pediatric intensive care unit (PICU) is well-recognized, with up to 32% of the parents in PICU fulfilling DSM criteria for Acute Stress Disorder (ASD) and 10.5% to 21% fulfilling criteria for Post-traumatic Stress Disorder (PTSD) [1-4].

Unfortunately, these quantitative studies did not fully explore the sources of parental stress and potential mitigating factors [5].

Shudy et al [6] reviewed the literature on the impact on parents of pediatric critical illness and injury and identified numerous stressors in PICU such as the environment, the child's physical appearance, invasive procedures and the loss of parental role. Sources of stress were mainly related directly to their child's illness or treatment, and only one study [7], identified something happening to another patient as a stressor.

Technological and physical aspects of the PICU environment have traditionally been identified as sources of parental stress, rather than the human social environment. However, studies have begun to examine the impact on parents of the things they see and hear unrelated to their own child. Talking to other parents in the waiting room was considered helpful to some parents, but stressful to others [5]. Colville and Gracey [8] found that sights and sounds were significantly associated with post-traumatic stress symptoms and parents may be traumatised by other events they witness on the unit (e.g. resuscitation or death of other children, distress of other families). Colville et al [9] confirmed that parents experienced high levels of anxiety in relation to what they saw and heard on the unit. Gaudreault et al [10] examined the experiences of parents witnessing the resuscitation of other children in PICU and found that while this was distressing for most, it was comforting for some.

Cardiopulmonary arrests, resuscitations and deaths are relatively common in the PICU and parents of long-term patients may witness multiple such events. Experience suggests that

parents may find observing such events in PICU distressing and their longer-term psychological health may be affected. Alternatively, it is possible that in the wider experience of their child's time in PICU, parents may find such observed events relatively insignificant.

Emotional trauma can occur "when someone is exposed to intense, distressing events either directly, by observing others experience the trauma, or vicariously, by learning of other's traumatic events" [11]. Trauma experienced by parents/carers as a result of their own child's illness and treatment has been called "treatment-related trauma" [11]. Observed trauma is defined as traumatic events that parents/carers experience while in the PICU unrelated to their own child's illness or treatment.

This qualitative study was designed to explore the experiences of parents/ carers of children admitted to PICU in order to identify observed trauma and understand its subjective short-term impact.

## **Materials and Methods**

Approval for the project was granted by the local Ethics Committee and parents were required to provide written consent.

Interviews and initial data analysis were done by research assistants who were medical students (MW and LA). They were trained, briefed and supervised for the project by the senior researchers (SK, JF, SR)

Participants: The setting was a 19-bed mixed medical/surgical PICU in a Pediatric teaching hospital in Sydney, Australia. The sample was drawn from a cohort of families of children admitted to PICU longer than 48 hours, between July and September 2010. All eligible families were approached for consent by a senior PICU staff member while their child was still in the unit.

Exclusion criteria included children who died in PICU; those admitted following non-accidental injury; parents with pre-existing severe mental illness; parents under the age of 18 years; and parents with a moderate to severe intellectual impairment which, in the opinion of the researchers, would prevent them from providing informed consent.

Data collection: Face to face screening interviews were conducted with parents together or individually within 48 hours of discharge from PICU, either in an interview room or in the child's room if this afforded sufficient privacy. The screening interview was structured with all respondents being asked the same questions. Parental perception of their own child's condition was rated using a simple scale. Identification of observed trauma was through the question " while your child was in PICU, did you experience (see, hear, smell) anything unrelated to your own child's condition, that you found upsetting or traumatic?" Parents who self-reported observed trauma were interviewed a second time within 24 hours. The second interviews were semi-structured, guided by a questionnaire but allowing flexibility for participants to share their stories. Key ideas including the nature of the distressing experience, its emotional, cognitive and behavioural impact, parents' coping strategies and suggestions for practice change were explored. The interview guide is appended (Attachment 1).

Data analysis: Interviews were audio-recorded, transcribed and data was content-analysed to identify themes [12]. Each respondent was allocated a unique subject ID where M represents mother and F represents father. A research assistant (MW or LA) read and re-read each interview to identify key statements based on the interviewees' descriptions of their experience. The condensed meaning of each statement was extracted by identifying and retaining only key words and these were again condensed into codes or sub-themes of only a few words. Each initial interview analysis was reviewed by three senior researchers (JF, SK, SR) and the identified themes were discussed extensively to ensure rigour in the analysis.

## Results

A total of 131 parents/carers of 100 children were approached by one of the investigators for consent. Of these, 8 were excluded due to information obtained during the consent process and 15 could not be interviewed within the scheduled time limit of 48 hours after discharge from the PICU. Eight parents declined to take part, and the reasons for this were not explored to avoid any perceived pressure to participate. The final screening interview sample was 100 parents of 91 children.

Prevalence of observed trauma: Of the 100 parents interviewed, 19 (19%) reported observed trauma. Of the 19, 1 parent declined to continue with a further interview and 7 were unable to be interviewed a second time due to the discharge of their child from the hospital. Second in-depth interviews were held with 11 parents. Sample characteristics are shown in Table 1.

Table 1: Sample Characteristics

(n=11)			
	Mean	Median (min - max)	
Age of child (months)	24	5 (0 - 176)	
Duration of stay in PICU (days)	20	8 (2 - 139)	
<b>Sex of child</b>		<b>Room</b>	
Male	6	Single	2
Female	5	Shared	9
<b>Relation to child</b>		<b>Previous admissions</b>	
Mother	9	Yes	5
Father	2	No	6
<b>Diagnosis child</b>		<b>Parental perception of own child's condition</b>	
Circulatory	4	Life threatening	5
Respiratory	4	Extremely serious	2
Neurological	1	Serious	3
Other	2	Stable	
<b>Cultural Identity</b>		<b>Admission</b>	
Australian	7	Booked	6
Other	4	Unbooked	5

The reported experiences included: the appearance of other patients, seeing children in distress or pain, the death of a child, overhearing information or conversations, hearing buzzers or people crying, the deterioration of another patient, seeing other parents in distress. Some of these occurred in the PICU itself but many parents reported being exposed to distressing things by simply being in the hospital – in the shared waiting area outside the PICU and Neonatal ICU, the parents’ lounge in PICU or travelling in the lift with other PICU parents. Some parents mentioned being upset by news media reports about children admitted to the unit.

The interviews ended with parents being asked if the experiences they had talked about were still impacting on their lives and while some said they still thought about it or would never forget it, all respondents denied ongoing difficulties in the early post-discharge period when they were interviewed.

Consistent with the literature [6], most of the parents interviewed reported that the impact of observed trauma was minor compared to the stress caused by their own child’s condition. Some, however, found it to be a significant source of stress. One mother said *‘I was probably more distressed by what I was seeing than what was going on with my own child’ (M003)*. Another said *‘it’s pretty intense; it’s not an environment you’d wish for your worst enemy to be in’* and *‘being exposed to that at a time when you’re already feeling quite emotional and vulnerable is....an extra factor that contributes to your stress.’(M006)*.

Thematic analysis of the interview transcripts yielded deeper insights into just how observed trauma impacts on parents. Five of the main themes are discussed below.

1. Involuntary Exposure: A number of parents reported that they could not avoid being exposed to what was happening to other children and families. This happened in the PICU or in public areas of the hospital: *‘just the fact that you’re in there and you do hear other things*

*happening, which is uncontrollable (M008)* and *'we just heard the doctors talking, and the nurses, and it's not really as private as what it could be (M003)'*. For some, this violation of the privacy of others caused a degree of discomfort: *'I asked the lady 'could you shut the curtains?' ..... 'cause I feel bad that I'm looking'* and *'it's not right that I'm seeing that (M067)'*.

A few parents regarded their involuntary exposure to other patients and parents as an unwelcome distraction from providing care for their own child. They reported trying to shut out the other things going on, as a way of coping: *'it is upsetting you know, so I was just trying to look away'* (F041) and *'you sort of want to focus on your thing and you've got these other things going on around you'* (M003).

2. Privacy and Confidentiality: Six parents were very aware of the right of patients and other parents to privacy, just as they needed their own privacy protected, but some also wanted to share other parents' experiences, either to offer support to them or because they found it helpful as a way of coping with their own child's illness. *'I think maybe knowing what the other patients were going through.....might have helped.... But I certainly respect their privacy'* (M082).

Nine of the parents who were interviewed in detail had children in shared rooms in the PICU. While many recognised the better privacy afforded by a private room some also acknowledged the practical reasons why every child could not have a private room and also the value of being connected to other parents: *'do you isolate every single person and not have that contact with other parents, not have that encouragement?'* (M082). One mother's comments seemed to sum up parents' ambivalence about single rooms: *'you can't just have everyone shut off in their own room and just to deal with your own problems, because there'd be cons in that as well, 'cause it's nice to be with people and see that there are other people*

*going through the same thing as you, so you don't want to be isolated. But then again, too much involvement.....it's hard' (M006).*

3. Empathy for children and their families: The experience of parents in PICU connecting with other parents and empathising, or in some cases identifying, with them was a strong theme in the interviews. Almost all parents mentioned the empathy or sympathy they felt for other PICU patients and families and this empathy demand did seem to add to their stress: *'you feel for them and the situations that they must be going through'* and *'you hurt that little bit more for the parents'* (M058). Some described this as an automatic connection that just happened: *'once you do have one of your own there's this automatic .... connection that you have with other parents'* (M006). Some parents specifically mentioned the distress they felt at seeing children suffering: *'heart-breaking'* (M015, M058, M067, M082) and *'they're just so small and helpless and they can't verbally tell you that they're in this much pain'* (M082).

In some cases this concern continued beyond the PICU admission with some parents at the time of interview still wondering about other children and families and wanting feedback about how they were coping, for example after their child's death.

4. Staff communication in PICU: The value of information and timely communication from staff is another theme which ran through the parents' stories. Many mentioned their need for information and reassurance at the time of the incident and expressed appreciation when staff recognised the impact on parent onlookers: *'they try to make it as easy as possible for other parents around ... they talk to you about it....not personally...just to try and put your mind at rest'* (M058). People's right to privacy was again raised by some parents in this context; one mother witnessed a child having a seizure, something new and upsetting for her, and she said *'cause the nurse couldn't tell me anything about it, you automatically assume the worst...'* (M067). This mother felt that she could have been given some appropriate information without violating the child's privacy: *'just a bit more reassurance, to say like*

*‘yeah, that’s natural for him’ .....they didn’t have to give me information because I understand privacy’ (M067).*

5. Reflection and Personal Growth: For seven of the parents, the experience triggered a process of reflection making them consider and/or compare their own situation in the context of what they saw or heard. Some parents construed the experience as positive as they felt they gained strength from the situation, while for others it brought up fears and concerns about their own situation. As one mother reported: *‘I just put myself in their shoes ..... is this going to happen to me?’* On further reflection she said: *‘it’s a good thing you learn from, because it made me stronger’ (M015).*

For many of these parents the experience left them feeling grateful for their own situation: *‘relief that you are not walking in those shoes, which is a horrible thing to say, but you know you are always going to be grateful your children are healthy’ (M046).* For some, these thoughts of relief and gratitude were coupled with a sense of guilt that their own child was doing better: *‘it’s just the human part of everyone that they want to know how the other person is doing, cause they want to make sure their child is doing better’ (M082).*

Being exposed to traumatic events in PICU provided new insight and awareness for some parents that the world is not perfect. One mother reflected: *‘in a perfect world this hospital wouldn’t even exist’ (M006).* Another reported on a conversation she had in the lift with a parent whose child had died in a drowning accident: *‘so many times as a mum things happen so fast and you don’t realise you know, you are aware of certain things but think that won’t happen, and it does happen’ (M035).*

## **Discussion**

This study represents a step in understanding the complex responses of parents/carers to the upsetting things they experienced in PICU. The incidence of observed trauma among parents was 19% making it important to acknowledge its occurrence and impact and consider practice improvements to reduce its incidence.

Parents/carers remember traumatic events they have witnessed and the impact it had on them at the time, and it adds to their general overall level of stress. The themes which emerged from the interviews here reinforced some of those identified by Gaudreault and Carnevale [10]

Whilst some of the traumatic experiences described by the group cannot be avoided within the PICU, it is important to consider what interventions may be helpful to minimise the impact of the experience and facilitate coping. Attention to patient privacy by medical and nursing staff where possible (e.g. drawing curtains during procedures), awareness of ‘other parent’ witnesses to potentially traumatic events and timely communication and support from staff during and after the event were among the interventions described as being helpful. Staff awareness and education on both the positive and negative effects of observed trauma are crucial and in our unit this has been incorporated into training for nursing staff, junior medical staff and allied health practitioners.

Social workers and other staff in hospital wards who see children and parents who have come from the PICU need to be aware of the potential for, not just treatment-related trauma, but observed trauma as well. The findings are likely to be relevant in other settings in the hospital as well, such as the Emergency Department and recovery ward.

This study found that exposure to observed trauma can occur outside of the PICU such as shared waiting areas, lifts etc., as a natural result of parents connecting and sharing their stories. Potentially all hospital parents, not just those in critical care areas, are vulnerable to this phenomenon, and therefore all hospital staff have a responsibility to be aware of the potential for observed trauma and be prepared to provide support and counselling for those parents who are negatively affected.

While all parents interviewed were clearly upset by their experience and its involuntary nature, and felt strong sympathy or empathy for the other child or parents, these experiences were not wholly negative. Some found a positive role in offering support to other parents. Others found knowledge of what was happening to other children helpful in making sense of, and coping with, their own situations. Some parents reported that seeing other children or parents having a difficult time actually made them feel stronger. Suggestions in these parents' narratives of elements of post traumatic growth have been reported in other studies [13] and further research to explore this phenomenon within the PICU setting would be useful.

Strengths and Limitations: As far as we are aware, this is the first study to focus on parents talking about their experiences of observed trauma in PICU. By allowing parents and carers to self-define what was upsetting for them, it explored a range of experiences rather than the impact of a single clinical event. Some respondents commented that the interview itself was helpful.

Given that the themes were drawn from the responses of only 11 parents it is not possible to claim that additional themes would not be identified in further interviews, or that the themes are representative of the majority of parents in the PICU or generalizable to other settings. This was an exploratory study but it does suggest that further study of observed trauma is warranted.

This study did not include a formal assessment for ASD/PTSD, and it focussed only on short-term impact, therefore no conclusion can be drawn about the longer-term impact, if any, of observed trauma.

It is possible that this study presents a conservative picture of the prevalence and impact of observed trauma as those parents excluded from the study and those who declined may also have had relevant experiences. In addition, some of the interviews were quite brief as not all respondents who identified observed trauma were able to reflect and report verbally on their experience.

The two research assistants (MW and LA) were medical students who were specifically trained to conduct interviews and supervised by two Social Work researchers (JF and SK). While they were able to collect valuable data in a sensitive manner, it is possible that more experienced interviewers may have been able to draw more lengthy responses.

This study was set up to include all parents in PICU regardless of gender, culture or language and it did capture the voices of some fathers and people from a variety of cultural backgrounds. However, all the respondents who were interviewed in depth spoke English and the results tend to reflect the experiences of mothers rather than fathers.

## **Conclusions**

Although observed trauma does not show up strongly in other studies with parents compared to issues relating to their own child (i.e. it is not mentioned spontaneously by parents) and therefore does not appear to be a major factor in parents' overall experiences in PICU, we found it to be a relatively significant phenomenon with 19% incidence in our sample. While its contribution to parents' overall trauma may be small, recognising,

preventing and responding to this need may contribute to a reduction in overall parental stress and emotional trauma. Ongoing education and training should be provided to assist nursing, medical and allied health staff to recognise and intervene in situations where parents on the PICU are witnessing traumatic events.

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