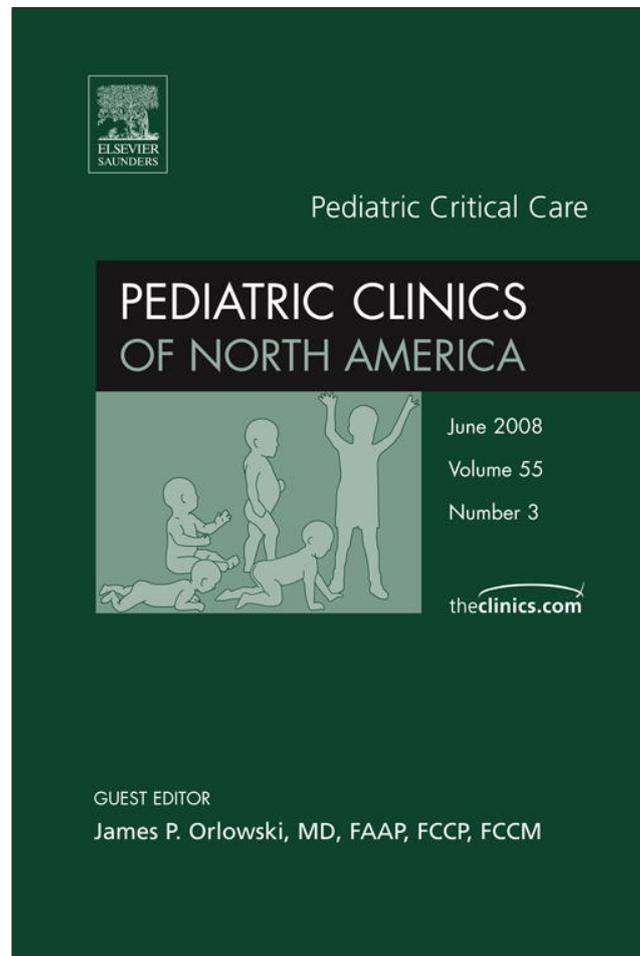


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The Psychologic Impact on Children of Admission to Intensive Care

Gillian Colville, MPhil^{a,b,*}

^a*St. George's University of London, London, UK*

^b*Paediatric Psychology Service, St. Georges Hospital, 2nd Floor Clare House,
Blackshaw Road, London SW17 0QT, UK*

In the first issue of the *Pediatric Clinics of North America* to cover the topic of pediatric intensive care, Rothstein [1] described our knowledge of the psychologic impact of critical illness on the child and family as “still quite rudimentary.” Nearly 3 decades later we have a much better understanding of the impact on the family [2–4] yet relatively little is known about children’s understanding of what happens to them or their longer-term psychologic recovery, despite the increasing numbers of children going through this experience (estimated at more than 200,000 annually in the United States, on the basis of recent admission rates [5]). In this article the current evidence on the psychologic impact on children of admission to the pediatric intensive care unit (PICU) is reviewed.

Literature review

Following consideration of the methodologic difficulties inherent in this field, the available evidence relating to the following questions is examined:

- What do children remember about their time on the PICU?
- What is the evidence that they suffer short-term distress?
- What is the evidence that they suffer long-term distress?
- Which variables are associated with poorer psychologic outcome?

Summaries of the main characteristics of the most recent studies discussed are provided in [Tables 1 and 2](#). Other studies of heterogeneous PICU samples, performed before 2000, are also referred to as appropriate,

* Paediatric Psychology Service, St. Georges Hospital, 2nd Floor Clare House, Blackshaw Road, London SW17 0QT, UK.

E-mail address: g.colville@sgul.ac.uk

Table 1
Recent studies of children's memories of the pediatric intensive care unit

First author	Date	n	Country	Age range	Length of follow-up	Informant	Main findings
Playfor [10]	2000	38	United Kingdom	4–16 y	2 d to 4 mo	Child	66% remembered PICU; recollections predominantly neutral; two reports of strange dreams
Colville [11]	2004	15	United Kingdom	7–15 y	8 mo	Child	13/15 had some memory; 2 children recalled nightmares
Karande [12]	2005	50	India	5–12 y	<5 d	Child	100% remembered PICU; 74% reported pain; 26% saw dead body
Board [13]	2005	21	United States	7–12 y	24 h	Child	67% remembered something; 33% remembered invasive procedures
Colville [14]	2006	102	United Kingdom	7–17 y	3 mo	Child	63% report factual memory; 32% report delusional memory; delusional memory associated with duration of sedation

Table 2
Recent studies of children's behavior and distress after pediatric intensive care

First author	Date	n	Country	Age range	Length of follow-up	Informant	Main findings
Rennick [19]	2002	60 + 60 controls	Canada	6–17 y	6 wk; 6 mo	Child	No differences between groups
Colville [24]	2004	48	United Kingdom	0–15 y	8 mo	Parent	No evidence of elevated behavior problems but 60% mothers reported change in relationship
Colville [11]	2004	15	United Kingdom	6–15 y	8 mo	Child	27% children report significant PTS but also report fewer fears
Rees [17]	2004	19 + 27 controls	United Kingdom	5–18 y	7 mo	Child	21% PICU children reporting PTS versus 0% general patients
Rennick [18]	2004	60	Canada	6–17 y	6 wk; 6 mo	Child	Invasiveness of treatment associated with PTS
Board [13]	2005	21	United States	7–12 y	24 h	Child	Intubated children used fewer coping strategies; anxiety associated with lack of memory
Small [21]	2006	163	United States	2–7 y	3 mo; 6 mo	Parent	Negative behavior associated with maternal anxiety, marital status, previous behavior, and child age
Colville [14]	2006	102	United Kingdom	7–17 y	3 mo	Child	27% reporting significant levels of PTS; main predictors were emergency admission and delusional memory

Abbreviation: PTS, posttraumatic stress.

but research relating to specific subgroups of PICU patients (eg, cardiac patients) is not included.

Methodologic difficulties

Truog [6] has emphasized the need for more research on the child's experience of critical care but this work is difficult to do for several reasons. By definition, children in the PICU are critically ill. It is therefore not usually possible to talk to them acutely because they are unconscious or heavily sedated. Also, although the age range of patients treated in the PICU is 0 to 18 years, most children admitted are younger than 2 years of age [7], which has implications for direct communication with children and the assessment of their psychologic distress.

Furthermore, there are clearly ethical issues about approaching families to take part in research while they are still in the PICU, when they are easiest to locate, because the child may die during admission and also has an elevated risk of death after discharge. Ethics committees are also traditionally reluctant for families to be approached after traumatic events, although there is mounting evidence that people taking part in such research do not regret it later and may even find it therapeutic [8,9]. Even when the child is out of immediate danger, parents' ability to give informed consent could be questioned on the grounds of their high levels of anxiety. They are also understandably protective of their children and consequently not always prepared to involve them in research, particularly if they realize this will involve discussion of traumatic events.

Longitudinal follow-up work is especially difficult because PICUs tend to be sited in large hospitals in urban centers, with the result that the distances families live from units are sometimes substantial. Many families have limited means [2,7] and so have limited access to resources, such as private transport; therefore it is not easy for some families to attend regular follow-up appointments at the base hospital.

What do children remember about their time in the pediatric intensive care unit?

Four recent cross-sectional studies have looked specifically at what children remember about their time in the PICU. Playfor and colleagues [10] interviewed 38 children about what they remembered and found that two thirds remembered something about their admission. However, although a third remembered being in pain and a couple reported having had nightmares at the time, few remembered being intubated. Given their findings that most children's recollections were neutral, the authors propose that their lack of recall for negative experiences in the PICU may protect against development of posttraumatic stress, citing the specific amnesic effect of benzodiazepines in this context. Colville [11], however, in interviews with

15 children 8 months after discharge, found that several did not fully understand what had happened to them and were not, as the authors of the previous study had supposed, reassured by their lack of memory. In fact 6 children said they would like to revisit the unit to try to see if they could remember more:

“I think I lost about 2 or 3 weeks.” (13-year-old girl, spinal surgery)

“Most of the time, it felt like I was going asleep for two minutes, then waking up—it felt like—days later. When I woke up, I asked my mum if I was dead—all I could see was white.” (15-year-old girl, epilepsy)

It was also striking how clearly some children remembered disturbing dreams so many months later:

“I had this really horrible dream, ...there was these three men ...and they put this ladder up and they got into our room and they gave us all this glue stuff ... and I went and I told daddy and he said ‘Don’t be silly, they are just repair men’ ... but they had poisoned us.” (9-year-old girl, cancer)

“I fell asleep and dad was holding my hand, and then I saw these people getting their heads chopped off.” (11-year-old boy, asthma)

In another study of children’s recollections of the PICU performed in a unit in India [12] with a much higher mortality rate ($>30\%$), children’s reports of being disturbed by pain and by witnessing the fate of other patients led to changes in the unit’s protocols regarding sedation and analgesia. In contrast, and possibly reflecting different sedation practices, Board [13] found in interviews with 21 children the day after discharge that although most children remembered something about the PICU, only a third remembered invasive procedures and many had positive recollections of staff and family.

Finally, in a larger study ($n = 102$) in the United Kingdom, Colville and colleagues [14] found that 1 in 3 reported delusional memories, such as nightmares or hallucinations, which they could still vividly recall 3 months after discharge. Although most children in this study (63%) remembered something factual of their PICU stay (see Fig. 1 for an example of what one child remembered of his stay), their memories were fragmented, with only 20% remembering being intubated.

What is the evidence that they suffer short-term distress?

The largest study to date of children’s behavior while still in the PICU remains that of Cataldo and colleagues [15], who made a series of 708 structured behavioral observations of 99 patients. Although more than half of this sample were asleep or heavily sedated, one third were awake and alert, but for the most part disengaged with their environment. A subsequent, and often quoted, observational study by Jones and Fiser [16] in 1992 found that PICU patients ($n = 18$) exhibited higher levels of distress than other pediatric patients in the days immediately following extubation. Board [13], in

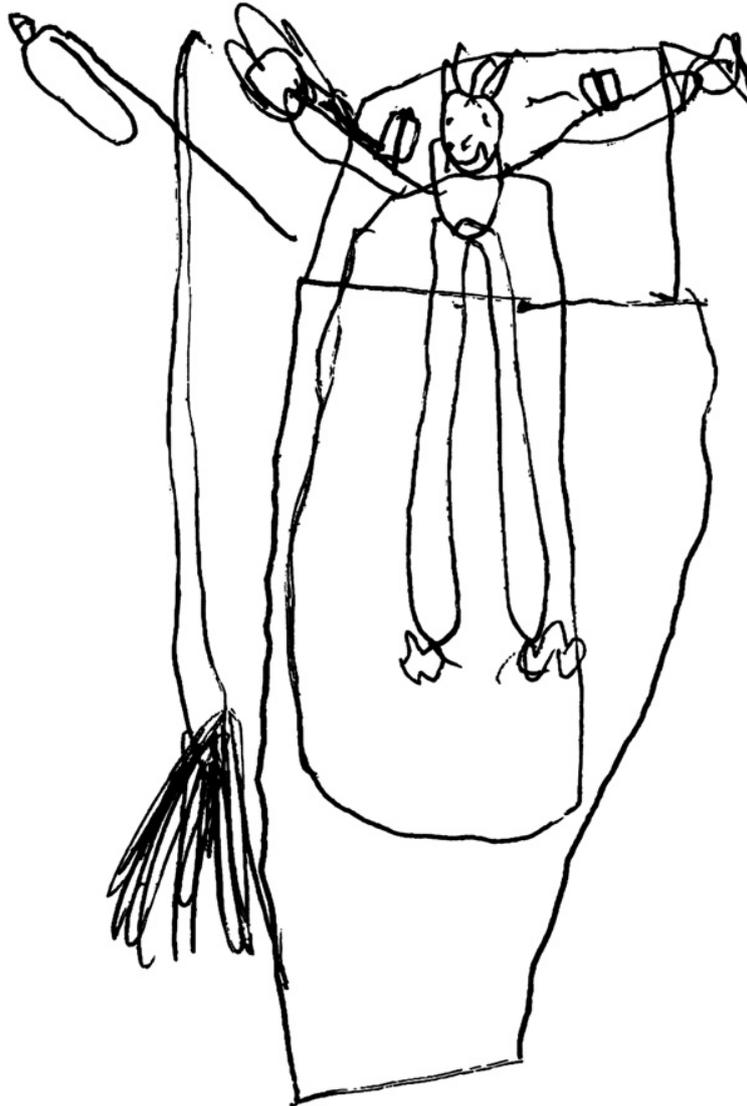


Fig. 1. Drawing of the PICU by a 7-year-old boy admitted with diabetic ketoacidosis.

contrast, reporting more recently on direct interviews with 21 children interviewed the day after discharge, did not find high levels of anxiety in the children in her sample but noted that they were still spending long periods asleep at this stage.

What evidence is there that they suffer long-term distress?

Rees and colleagues [17] in a cross-sectional cohort study 7 months after discharge found significant rates of posttraumatic stress in 19 PICU patients in clinical interviews. One in 5 children reported clinically significant levels of posttraumatic stress and, in particular, elevated rates of avoidance. Colville and colleagues found similar rates of posttraumatic stress in two separate interview studies at 3 and 8 months after discharge [11,14]. Another group following a sample ($n = 60$) at two separate time points by postal survey found, worryingly, that most children who had significant levels of posttraumatic stress at 6 weeks were still reporting high levels at 6 months [18].

There are mixed findings regarding comparisons with rates of distress in control samples of pediatric patients. Rees and colleagues [17] found a significant difference between groups, with no child in the control group meeting criteria for a diagnosis of posttraumatic stress disorder. Rennick and colleagues [19] found no differences between groups, however, echoing the earlier work by Youngblut and Shiao [20] who found, 2 to 4 weeks after discharge from the PICU, that parental report of behavior problems was similar to that reported in other studies of other hospitalized children.

Finally, there is also evidence that some patients believe they have changed in positive as well as negative ways as a result of their experiences. In particular, children in one study reported lower numbers of childhood fears than age- and sex-matched peers [11] and this quantitative finding was reinforced by their comments:

“I am a bit more grown up.” (9-year-old girl, cancer)

“Now when I get a cut, it is just nothing. I am not as scared as I was.”
(13-year-old girl, abdominal surgery)

Which variables are associated with poorer child psychologic outcome?

Several authors have found an association between premorbid behavior problems and the development of distress after being in the PICU [16,21], but for the most part studies have not found a clear relationship between the severity of illness, whether measured by length of stay or standardized mortality risk. The degree of life threat perceived by either the child or the parent has, however, been found to be associated with later distress in the child [17], just as the parent's perception of the likelihood of the child dying is significantly correlated with their own stress at long-term follow up [22].

Rennick and colleagues [18] found younger children and those who had undergone more invasive procedures reported more distress at follow-up at 6 weeks. The effect of age had diminished by 6 months postdischarge, but the effect of the number of invasive procedures had not. However, the authors did not demonstrate that the children remembered these invasive procedures and the evidence from studies of children's memories would suggest that many do not, so a simple association between memory for PICU procedures and subsequent development of posttraumatic stress cannot be assumed.

Despite previous anecdotal reports of a link between emergency intubation and posttraumatic stress [23], no such association has been found in more systematic studies, not least because of the small numbers of children actually remembering being intubated, although Board [13] did find that children intubated for longer time reported using fewer coping strategies on the general ward after discharge. Perhaps counterintuitively this study also found that children who did not remember their admission were more anxious than those who did. This finding was echoed by the

observation that two of the four children who had clinically significant levels of posttraumatic stress at follow-up in another study reported no factual memories of the PICU at all [11].

The evidence for a link with delusional memory is stronger. An interview study of 102 children [14] found a significant independent association between duration of sedation/analgesia and child's report of delusional memories, including hallucinations. The presence of delusional memory was in turn related to posttraumatic stress symptoms, and in particular intrusive thoughts, at 3 months. This last finding is consistent with earlier work demonstrating higher rates of observable anxiety in children receiving more sedative agents [16].

Another finding reported in several studies is that of a relationship between child and parent distress, although the direction of this relationship and the mechanisms underlying it are not well understood. Rees and colleagues [17] found an association between child and parent posttraumatic stress scores and Small and Melnyk [21], in a secondary analysis of a longitudinal intervention study, found that maternal anxiety within the first 24 hours predicted negative behavioral outcome in children at 3 and at 6 months. These findings suggest that parents' own emotional state during admission may impact negatively on the child's psychologic recovery. This possibility was acknowledged in a follow-up study, in which 48 mothers were surveyed about the long-term impact of admission [24]. Although for the most part they did not believe their child had changed, 60% believed their relationship with their child continued to be affected by the stress they had experienced on the PICU, 8 months after the child's discharge:

"I just feel my whole life revolves around just making sure (child) is OK."
(Mother of 1-month-old girl, bowel surgery)

"I don't let him to go to sleep on his own and I think that is definitely from intensive care. I wake up the second he makes a noise." (Mother of 1-year-old boy, meningitis)

Discussion

In summary there is mounting evidence that a significant minority of children suffer lasting psychologic problems following their treatment in the PICU. The recent evidence is particularly compelling because, in the past 10 years, greater research effort has been directed at eliciting information directly from the children themselves, rather than relying solely on either observed behavior or parent report. Also there is now a growing evidence base on the long-term psychologic reactions of these children, quantified using standardized psychologic measures, with less reliance being placed on anecdotal report in this field. Reports of children's recollections have not usually been combined with follow-up measures of distress in the longer term, however, making it difficult to determine what it is about the child's subjective experience of the PICU that puts them at most risk for a poor psychologic

outcome. Another significant gap in the literature remains the description of the behavior of children aged less than 5 years, which is especially important given the high proportion of infants on the PICU [7].

The levels of posttraumatic stress symptoms reported by older children suggest that this is a population at risk that should be more routinely screened and monitored, given that there are established treatments available [25]. In this context, the importance of asking children directly about their symptoms has been stressed by researchers who have found a tendency for parents' own levels of posttraumatic stress to affect their estimations of their child's distress [26–28].

The association between parental and child psychologic state also warrants further investigation. The seminal work of Carter and Miles [29] has shown that it is the interpersonal aspects of the PICU experience, such as the impact on parent's role, that are experienced as most stressful by parents during admission, and we now know that parents exhibit elevated distress levels in relation to their experiences for many months after their child is discharged [17,22,30,31]. More generally the tendency for parents to be over-protective in caring for their child after life-threatening events is a phenomenon that is well known to pediatricians [32] and that has been shown to lead to problematic family functioning [33].

Several children described disturbing nightmares and hallucinations, which were similar in content to those described by adult intensive care survivors [34], suggesting that this is another aspect of their experience that merits further systematic exploration, especially given the association, found in adults, between delusional memories and the development of posttraumatic stress [35].

The finding, in one study, that children reported positive as well as negative changes [11] may simply reflect that the convenience sample used was atypically resilient. It may, however, be evidence of a phenomenon that is currently attracting a great deal of interest in the traumatic stress literature, namely posttraumatic growth [36], which commonly coexists with posttraumatic stress. To date, only a couple of studies in the wider pediatric traumatic stress literature have described this in children [37,38].

Implications for future research

More longitudinal studies are needed to clarify the natural history of psychologic adaptation of children in this situation [39] and to clarify which aspects of the child's experience related to injury, illness, or treatment are associated with poorer psychologic outcome [40]. Specifically there is a need to develop tools for use across the pediatric age range to assess delirium and withdrawal [41,42], and to investigate associations with these aspects of experience and long-term psychologic well being. More information is also needed on the interactions, over time, between the parent's symptoms and the child's psychologic state.

A better understanding of the mechanisms underlying the development and maintenance of psychological distress in these children will inform the design of future interventions, such as the promising COPE package [43]. This intervention, in which timely advice is provided to parents on how to facilitate their child's adaptation to PICU treatment and its aftermath, seems to improve long-term psychological outcomes for children and parents alike, by reducing mothers' anxiety and increasing their participation in care [44].

Clinical implications

The literature has uncovered several aspects of the PICU experience that could theoretically give rise to adverse psychological effects in child patients and that have the potential to be addressed clinically, even while the child is still in hospital. The possibility that the child may be troubled by disturbing factual or delusional memories should be acknowledged, as should the child's confusion about what has happened to him or her. Age-appropriate explanations about the child's injuries, treatment, and side effects of treatment should be provided when the child is in a position to take this information on board. Written information in diary form has been well received by adult intensive care survivors [45], many of whom report being troubled by their inability to remember their admission. Case reports of individually tailored interventions with children highlight the importance of finding creative ways to impart information, reduce anxiety, facilitate communication, and prepare them for procedures during admission, along with helping them to process all that has happened, after discharge [46]. The high prevalence of anxiety in parents, when considered with the evidence that this is associated with the child's psychological outcome, indicates the need to provide support for relatives during and after admission, when required.

Summary

The literature on the psychological impact of the PICU on children shows a mixed picture of resilience and distress. Children report disturbing nightmares and hallucinations associated with their admission and a significant minority have elevated levels of posttraumatic stress many months after discharge, indicating that there is a need for (a) more support for this group of patients, and (b) further longitudinal research into risk factors associated with distress. By understanding more about the range of psychological reactions of children in this situation, workers in this field will be better placed to identify those families most in need of support and to design appropriate interventions for them.

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