

6: The impact of admission to paediatric intensive care unit (PICU) on the child and family

GILLIAN COLVILLE

Introduction

The admission of a child to a paediatric intensive care unit (PICU) is, even when planned, a source of considerable anxiety for parents. An emergency admission represents a crisis for a family. There are suddenly many potential losses to be faced such as disfigurement, brain damage and, most feared of all, death. On PICU parents may, for the first time, be told a child's diagnosis. This can sometimes have catastrophic implications for the rest of the family, for example, if a baby is found to have a degenerative genetic condition or to be human immunodeficiency virus (HIV) positive. Initial relief that a child has survived may be replaced by the awful realisation that he or she will never be the same again. For some families, there is significant strain associated with the uncertainty of prognosis or increased dependency placed on the parent-child relationship, by the demands of chronic illness.

On admission the child may be very frightened by the deterioration in his or her condition and bewildered by the rising anxiety evident in their parents. On the unit they will often be subjected to numerous invasive procedures such as cannulation and suctioning. As they recover they may experience disturbing side-effects as their sedation is weaned and they become more aware of the distress of other patients and their families.

In 1993, the British Paediatric Association recommended that the special psychosocial needs of children on PICUs and their families be addressed [1]. However, 5 years later only 54% of paediatric units in the UK had a social worker on their staff. Only 31% of PICUs were supported by a psychologist and 19% had no dedicated psychosocial staff [2]. In practice, therefore, the job of addressing families' psychological needs mainly falls to the medical and nursing staff.

Literature on parents' experiences of intensive care

There is evidence that, during an admission to intensive care, significant numbers of relatives suffer symptoms of anxiety and depression [3]; however, there is little information on how long these symptoms persist after discharge. Higher levels of anxiety are reported in relatives with lower rates of contact with medical staff, and as many as half have problems understanding the patient's diagnosis [4]. Also, the effectiveness of interventions designed to tackle communication problems is unknown.

In a comprehensive review of studies of parents' experiences and needs while on PICU, Noyes [5] found that the data were predominantly quantitative, written from a nursing perspective and North American in origin. Youngblut and Jay [6] identified the following areas as giving rise to the highest levels of concern: the child's survival, the possibility of brain damage, seeing the child in pain and the diagnosis. The environmental assault of ICUs on the senses (referred to as 'sensoristrain' by Black, Deeny and McKenna [7]) has been assumed to exacerbate parents' distress. However, the principal finding of Carter and Miles' work [8] was that the main strain for parents was the disruption of their parental role, with mothers exhibiting higher levels of stress than fathers [9] (Figure 6.1). Furthermore, it has been demonstrated that stress-related symptoms in mothers persist for months after discharge and are consistently higher than those of mothers of children admitted to a general ward [10]. Lastly although there is

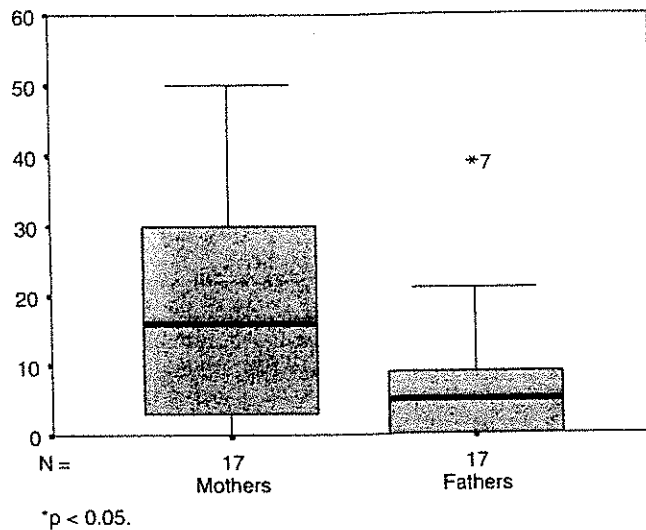


Figure 6.1 Mothers' and fathers' scores on the Impact of Events Scale (IES). Scale scores reflect number of post-traumatic stress symptoms, with scores over 20 regarded as clinically significant and scores over 35 suggestive of full post-traumatic stress disorder (PTSD).

Box 6.1 The reported positive aspects of parents' experience on PICU

- 'Because of the accident, he is very, very, special to me'
- 'We saw the best of people during that time'
- 'I re-valued my life totally. This house could burn down tomorrow as long as my family stood out there I wouldn't worry'

evidence that parents' memories of events during admission remain vivid for a long time after discharge [11,12], it is important to be aware that parents report positive as well as negative experiences and, in the longer term, the majority cope remarkably well [13] (Box 6.1).

Literature on the child's experience of intensive care

The literature on adult survivors of critical care contains descriptions of distressing memories relating to painful and frightening experiences, including fear of death and the inability to communicate while intubated [14]. Much less is known about the experience of children in this situation. Distress in a conscious child during admission may present as marked lack of engagement or as active resistance. The latter directly impacts on the child's medical condition; an anxious child may resist mechanical ventilation, and associated increases in heart and metabolic rate place further demands on an already critically ill patient. Ambuel *et al.* [15] point out the limitations of many commonly used behavioural distress scales (which are primarily intended to measure acute pain in relation to discrete procedures) when applied to this population. They have developed a useful observational scoring system for measuring distress in the PICU setting (the COMFORT Scale), which takes account of the child's limited opportunity to communicate or move, and which can be used for continuous observation.

Post-traumatic stress symptoms have been described in three children following intubation [16], as well as 'out of body' or 'near death' experiences [17]. The quality of sleep on intensive care is another issue that has been examined on PICU. Normal sleep stages are not seen and rapid eye movement sleep is absent [18]. Playfor [19] found that only 60% of children remembered their admission, and that their memories were predominantly neutral or positive (Box 6.2 and Figure 6.2). However, two more recent studies [20,21], which employed standardised psychological measures and followed up children over a longer period, have reported significant levels of post-traumatic stress in survivors of PICU.

Box 6.2 The reported views of children after PICU admission

- 'I am not as scared as I was – now when I get a cut it is just nothing'
- 'I think I am a bit more grown up'
- 'I feel like I am the odd one out of everybody'
- 'I really miss the way I was before'

What I remember about PICU

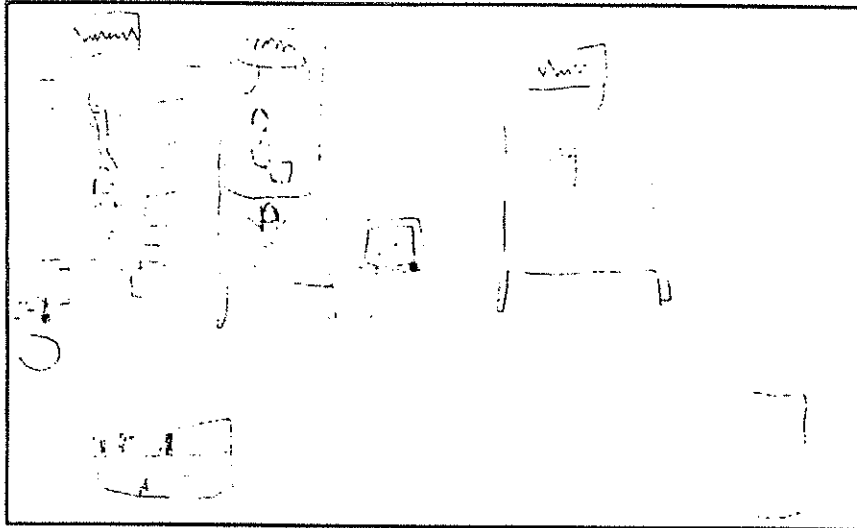


Figure 6.2 A child's perspective of PICU.

A recent study [22] exploring the hospital experiences of a group of ventilator-dependent children concluded that prolonged PICU admission has a 'profound and negative impact' on the quality of life of this particular subgroup of patients who may require more psychosocial input [23]. The fact that such children are often more aware of what is going on around them than other patients on PICU means that they are more likely to be affected emotionally by separations from family, by having multiple carers, and being at much greater risk of witnessing untoward events [24]. An increasing number of these patients are spending long periods in intensive care because of practical problems arranging discharge [25].

Research on parents at St George's

In order to establish the degree of psychological distress in parents following their child's admission to PICU, and identify factors associated with poor psychological adjustment, 52 parents were interviewed about their memories of PICU and current psychological functioning, 8 months after discharge. Measures included the Parental Stressor Scale (PSS: PICU) [8], the General Health Questionnaire-28 (GHQ-28) [26] and the Impact of Events Scale (IES) [27]. Significant rates of psychological distress were found, with 60% of the sample scoring above accepted cut-offs on either GHQ-28 or IES. Distress was not associated with child demographic or medical variables but was associated with subjective rates of stress during admission as measured by the PSS: PICU (Figure 6.3). Parents who talked about their feelings at the time of the admission had lower IES scores at 8 months than those who did not; the majority of parents would have appreciated the offer of a follow-up appointment [28]. Parents who wanted a follow-up appointment reported higher scores on PSS: PICU and IES than those who did not (Box 6.3). Although satisfaction with care on PICU was generally high, parents frequently described harrowing experiences before admission (echoing comments from a previous study evaluating parents' experience of patient retrieval [29]) and afterwards on the general wards. Where dis-

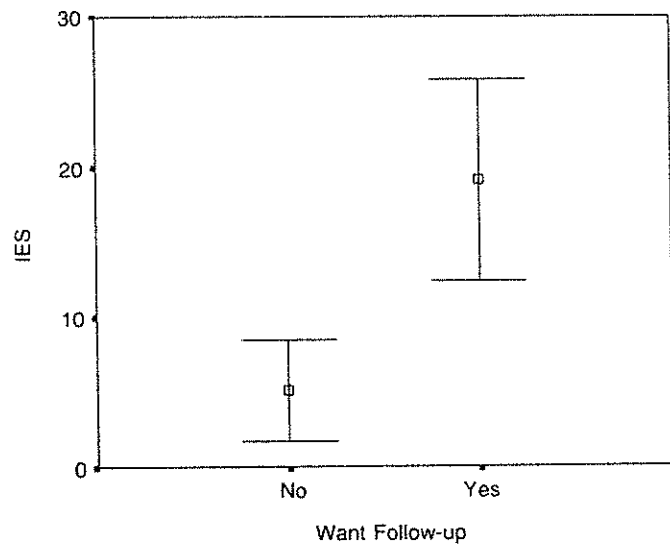


Figure 6.3 Distress levels in parents ($n = 52$) as measured by their responses to the Impact of Events Scale (IES) scores, divided into parents who did or did not want follow-up support. The threshold value for clinical concern is 20.

Box 6.3 Dimensions measured by the Parental Stressor Scale (PSS): PICU

- Child's appearance
- Procedures
- Sights and sounds
- Staff behaviour
- Parental roles
- Child's emotional and behavioural responses
- Staff communication

were available for both parents, mothers reported significantly higher rates of distress at follow up than fathers [30].

Given the finding that a significant proportion of families would appreciate further contact after their child's admission, it was decided in a subsequent prospective study, to offer a follow-up clinic appointment with PICU staff randomly to half a cohort of families of surviving children over the course of 1 year. Preliminary results suggest that although these appointments have been well received when parents have taken them up, only a minority of families have chosen to attend. Ongoing analyses will examine differences between those who attended and those who did not and explore the reasons for non-attendance.

Research on children at St George's

The author has examined two sources of information regarding children's experience of PICU: parents' reports of the degree to which they felt their child had been affected by the experience of being admitted to PICU [31] and direct interviews with a cohort of children aged over 7 years [32].

In the first study, the mothers of 48 children were asked, as part of a semi-structured interview 8 months after their child's discharge, about the impact of PICU admission on their children. Those parents whose children were aged over 2 years ($n = 22$) also completed a standardised behaviour questionnaire on their child's current psychological functioning [33].

Only 8 out of 48 mothers felt their child had been changed by the experience, with 10 out of 12 parents of children under 1 year, feeling the question was not applicable because of their child's age. However, 29 parents reported that their relationship with the child had changed. Parents described feeling closer to the child but also frequently fearful about the child's well-being. Most parents acknowledged that their relationship has

been altered by experience of PICU and were aware of continuing to be overprotective many months after the child was out of danger - a phenomenon well recognised by paediatricians in parents of children who have survived serious illness [34]. However, the children's distribution of scores on the behaviour questionnaire was normal, indicating that they were not exhibiting significant behaviour problems.

In the second interview study, 15 children were asked what they remembered of their admission to PICU and how much they still felt affected 9 months later, by which time they had usually recovered physically and were able to reflect on the experience. Standardised psychological questionnaires were administered: the child version of the IES [35], the Birmaher Child Depression Scale [36] and the Fear Survey Schedule for Children (FSSC) [37]. Interviews were held 9 months after discharge and in addition parents completed the Achenbach Child Behaviour Checklist (CBCL).

Although, as in the previous study, parents did not rate the children as having significant behaviour problems, six children scored in the clinically significant range on one or more measures, during direct interviewing. These conflicting results suggest there is a need for further research on the child's experience, and demonstrate that parents may not always be aware of the extent to which their child has been affected by their admission. Lastly, the way children responded to the FSSC was surprising in that they reported significantly fewer fears than age- and sex-matched peers. It is possible that this finding reflected the fact that only the most constitutionally resilient of children were prepared to be interviewed. It may however be a genuine reaction to surviving trauma, as some children clearly articulated during the interview.

Clinical implications

The scope for preparation is limited, given the acute nature of many admissions, but where admission to PICU is planned, it may be possible to introduce both child and family to the unit beforehand. Knowledge gained about the anxieties of the family at this stage may usefully inform future involvement with the family. For example, past negative associations with the intensive care environment need to be taken into account in understanding the special significance of an admission, however routine from the staff's point of view.

The main reasons for referral to the paediatric psychologist during an admission centre around management of the child's distress, communication and occupation. The procedures to which children are subjected whilst in intensive care are inevitably distressing and painful. Thus, good pain control is essential, particularly where a child is conscious; an effort should be made to schedule invasive procedures in such a way as to minimise distress [38]. It has been demonstrated that where PICU patients are

'conscious but markedly non-engaged', the introduction of age-appropriate activities increased positive affect and decreased inappropriate behaviours such as self-stimulation and interfering with medical equipment. Another simple intervention where a young child was given an environmental cue in the form of a red light (which was switched on whenever an invasive procedure was imminent) brought about a marked reduction in overall anxiety [39].

A child with some awareness of their surroundings on PICU may well become fearful while anticipating a procedure. This might be because they know from experience that it will be painful, or because they are so bewildered that they do not trust anyone. The well-established principles of desensitisation and adapting interventions to take account of the child's interests apply. A child may be referred for being uncooperative (e.g. for spitting into the nurse's eye whenever she attempts suction of secretions from the tracheotomy). In such a case, it can be very helpful to understand this behaviour in the context of the child's need for control over a situation where he or she feels overwhelmingly powerless, and where possible, adjust some of the parameters of PICU management accordingly.

In contrast to most patients on PICU, children who are ventilator-dependent may be fully conscious of what is going on around them and may be on the unit for some time. If available, the skills of a play therapist are often invaluable with these children. Advice should be provided on developmental appropriateness of play materials and the need for the children to gain some control over their surroundings. The usual pastimes of listening to stories or musical tapes and watching videos will soothe and lift a child's mood in the short term, but during longer admissions more varied materials should be offered, in the interests of the child's overall development and emotional well-being. A paraplegic child can derive all the usual pleasure afforded by doll play, if someone is on hand to follow his or her instructions. There is also a particular delight to be watching another messing around with paints, in this sterile, orderly environment.

For a significant number of parents, any discussion of their own emotional state whilst their child's medical condition is critical is simply too painful and regarded by them as an unwanted distraction. At this acute stage it is important to respect the parents' need to hold themselves together by whatever individual coping strategies they find helpful in the short term. Contact may consist of little more than gentle reminders to take breaks, sleep and eat, and an opportunity to discuss the logistics of visiting arrangements. There is also a place for providing normalising information describing how other parents have felt in similar circumstances. Advice may be sought as to whether siblings should be allowed to visit and about what they should be told. Parents may also seek guidance on how to handle a sibling's attention-seeking behaviour or separation distress.

It is often after transfer from intensive care to the general ward that the child's distress is most apparent. As the sedation wears off they become

Box 6.4 Parents' comments about their child's appearance

- 'She looked totally drugged, dazed, gone, she was just out, puffy'
- 'She just looked horrific, bright red face, tubes coming out of every possible place'
- 'She was so bloated and she looked terrible, I just could not make myself to go near her'

more aware of pain and begin to try to make sense of what has happened. At this point they may experience nightmares or hallucinations and be uncharacteristically wary and fearful. The side-effects of weaning off morphine and midazolam may temporarily render the child unrecognisable to close family [40] (Box 6.4). This can be very upsetting for parents who may be anxiously seeking evidence that the child is returning to normal, particularly if there has been any question of brain damage. Even if the child is not unduly distressed, there may be some value in a psychologist making contact with a family, where the circumstances that gave rise to the admission are known to have been traumatic. Information can be given, both about normal reactions after an accident and how to seek further support.

Subsequent involvement, after discharge, may take the form of intervention focusing on post-traumatic stress symptoms, help with newly acquired fears, particularly around further medical treatment or providing general support for the child and family. Older children sometimes appreciate being provided with a list of operations, giving names of procedures and dates performed, as they piece together details that are otherwise confused and sketchy.

Parents sometimes present clinically to the psychology service months later claiming that the relationship with their child has altered irrevocably since admission. They describe being aware of the fate of other children who died on the unit and report something akin to survivor guilt, albeit by proxy, which is experienced as especially troubling. In common with other trauma survivors, they no longer feel the world is a safe place and lose confidence in their ability to tell whether a child is ill or not, leading to increased rates of consulting behaviour both in primary and secondary health care settings.

Conclusion

It is important to strike a balance between acknowledging the strain on families on PICU and 'over-pathologising' their reactions. Whilst it is clear

that the admission of a child to PICU is often experienced as traumatic, for the most part it does not lead to severe psychological distress. More research is needed on the natural history of stress reactions in parents and children in this setting and into ways of identifying those at highest risk of developing long-term problems, in order that appropriate timely support can be offered to those most in need.

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