

Paediatric intensive care

Gillian Colville highlights the psychological stresses and strains for child patients and their families, and discusses some research challenges in this area

Until relatively recently it was assumed that as long as they were appropriately sedated, children on intensive care units were unaware of what was happening to them. But new evidence is emerging that they, like adult intensive care patients, can be troubled by disturbing memories of their treatment or of the circumstances that brought them into the unit and by hallucinations, which can affect their longer-term psychological recovery. Also, although the majority of parents cope admirably, it is now well documented that a minority of parents suffer clinically significant levels of distress in relation to these recollections. This article reviews the research in this area and considers the implications for clinical work and future research.

questions

Do children remember being critically ill?

How does critical illness affect the parent-child relationship?

resources

www.PICUpsychology.net – Gillian Colville's research, and links to key references in this field
 www.NCTSnet.org – The assessment and treatment of post-traumatic stress in children after a range of traumatic events, including those relating to their care in paediatric settings.

There can be few experiences as terrifying as watching on helplessly while your child battles critical illness – but this is the experience of the parents of over 18,000 children admitted to a Paediatric Intensive Care Unit (PICU) in the UK each year (PICANET, 2010). Also, until relatively recently it was assumed that as long as they were appropriately sedated, children in this situation were unaware of what was happening to them. However, new evidence is emerging that children can be troubled by disturbing memories of their treatment; of the circumstances that brought them into the unit; and of hallucinations they may have experienced during admission. These memories can then, in turn, affect their longer-term psychological recovery.

The age range of patients treated on PICU is 0–16 yrs, but the majority are aged under three years. Children are admitted to PICU for a wide variety of emergency medical and surgical conditions. These include endstage cancer; meningitis; burns; fractures; and respiratory problems, often relating to prematurity. Others are admitted electively for post-operative

monitoring. Approx 5 per cent of children die during admission and, for those who survive there continues to be an elevated risk of death in following year (PICANET, 2010). Although most survivors make a good physical recovery, some children are left with serious disfigurement, neurological difficulties or behaviour problems, such as those that may follow traumatic brain injury. Others will have ongoing disabilities relating to congenital problems or prematurity.

What do children make of it?

Children's memories of their stay on the PICU are usually either patchy or non-existent as they frequently spend long periods unconscious or heavily sedated. In a study of 38 children, Playfor et al.

(2000) found that only approximately two thirds of children remembered anything about their intensive care admission and their memories were mostly emotionally neutral in tone. In another study of 102 children, a similar proportion of children reported factual memories of their stay, but a third of the sample also reported bizarre nightmares and strange perceptual experiences in the early stages of their

recovery (Colville et al., 2008). Some examples of these memories, which were similar in content to those reported by adult intensive care patients, are given in the box, 'Hallucinations'. This phenomenon was previously referred to, in the adult intensive care literature, as

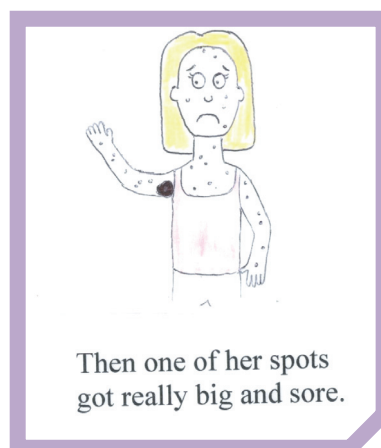


Figure 1: From a story book entitled 'The Big Spot' made for a three-year-old girl who needed treatment on PICU for necrotising fasciitis, a severe complication of chicken pox

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'ICU psychosis', but it is now usually attributed to delirium resulting from the patient's physiological instability and drug withdrawal side-effects.

There is an emerging literature on the longer-term psychological symptomatology of children treated in critical care settings, which consistently shows that a significant minority report high levels of post-traumatic stress symptoms for many months. However, the extent of this distress does not seem to be simply a function of the degree of severity of their illness or injury (Colville, 2008; Davydow et al., 2010). Children may, for example be distressed witnessing scenes relating to the resuscitation or death of another patient. There is also evidence that children treated on PICU report higher rates of post-traumatic stress than those treated on general wards (Rees et al., 2004) and that those who are sedated for longer are more likely to report delusional experiences and suffer higher rates of post-traumatic stress symptoms (Colville et al., 2008). What is as yet unclear, however, is the degree to which this distress is directly linked to events on the intensive care unit as opposed to the circumstances precipitating the admission to hospital in the first place, or traumatic experiences on the general ward (such as painful injections or dressing changes), once they have regained consciousness (Ward-Begnoche, 2007).

What is it like for parents?

It is important to acknowledge, as Affleck et al. (1991) observed in a landmark study of parents of children admitted to a Neonatal Intensive Care Unit, that the majority of parents in this difficult situation cope admirably. Also, and perhaps surprisingly, there is qualitative evidence that they appreciate a sense of humour in those caring for their child (Colville et al., 2009) and frequently report that they have been affected positively as well as negatively by their experiences (Colville & Cream, 2009). However, in contrast to the memories of their children, parents' memory for events

on the unit is often extraordinarily detailed, and it is now well documented that a minority suffer clinically significant levels of distress in relation to these recollections. Early studies of parents' experiences in this setting tended to focus on how parents felt while the child was still in intensive care, but recent longitudinal studies indicate elevated levels of anxiety and post-traumatic stress for many months after discharge (Balluffi et al., 2004; Bronner et al., 2010). They also report a tendency to be somewhat over-protective, even where the child has made a good recovery (Colville et al., 2008). As has been found in studies of children's psychological adjustment after PICU, the relationship with objective measures of severity of illness (such as number of days on a ventilator or number of injuries) is weak. Parents' subjective sense of the degree to which their child's life is in danger is a much stronger determinant of their later distress (Balluffi et al., 2004).

Psychological support

Supporting and facilitating parental coping in this acute setting and in the immediate aftermath of the child's discharge tends to be the psychologist's most common role. Parents often feel particularly vulnerable just after a child is transferred out of the critical care (Colville et al., 2009). As they have come to rely on the monitors and high staff ratios in PICU they are, at this stage, unnerved by the de-escalation of medical intervention, even though intellectually they may be able to see this as a positive development. The need to acquaint themselves with a new ward environment and staff group is a further strain. Also, at the same time they are required to play a larger part in caring for a child who is much more aware of what is going on and consequently often more demanding as they recover.

Later on, more formal trauma-focused interventions, such as narrative exposure therapy, may be indicated for the minority

Hallucinations

Examples of children's descriptions of hallucinatory experiences on the Paediatric Intensive Care Unit (Colville et al., 2008).

'I was certain that I got here on a yellow train.'
'I was hanging out of the window and someone dropped a van on my head.'
'A monster wanted to eat me – to eat me to bits.'
'I could see children at the bottom of my bed, they were laughing at me.'
'A cat bleeding on the ceiling.'

of patients and family members who continue to be very distressed by their most traumatic experiences. Narrative exposure therapy is a form of exposure therapy for patients with PTSD which encourages them to tell recount events chronologically to someone who writes it down, reads it back to them, and helps them integrate fragmented traumatic memories into a coherent narrative (Schauer et al., 2011). These events may have occurred in the run-up to admission (e.g. accident, rapid deterioration of medical condition) or during the admission itself (e.g. respiratory arrest, multiple invasive procedures, death of another patient on the unit). In practice, however, it is unwise to initiate such work until the child is out of danger and stable from a medical point of view, which may not be for several months. It is unlikely that the parent will be psychologically ready to revisit their experiences before this point. At this stage consideration should be given as to whether such treatment might be more appropriately provided by a local adult service, particularly if there is a history of previous mental health problems, or if the family live some distance from the base hospital.

It is not usually possible to communicate directly with the patient during their admission, but there are special situations where this is necessary

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(e.g. where a child is aware of their surroundings after extubation or is on long-term ventilation). Some ingenuity is required if the patient is unable to speak, either because of fatigue or because the ventilator tube is *in situ*. The use of diagrams or non-verbal methods of communication such as eye-blinking or hand-squeezing may be helpful on the part of the clinician. If the child is very confused, there is likely to be a need for the repeated provision of reassurance and basic, developmentally appropriate information about where the child is and what is happening. As it is common for a child to have no recollection of arriving on the unit, they are often quite disorientated with respect to both time and place.

Individualised storybooks – illustrated books written in developmentally appropriate language by the psychologist about the patient's condition and treatment – may help a child make sense of their experience once they begin to recover and may also facilitate a more open discussion about what has happened with other family members (see Figures 1 and 2). There is also a place for psychoeducation about the possibility that the child might experience perceptual disturbances in their early recovery and about the way in which post-traumatic stress symptoms may express themselves in the weeks and months following an admission. After a prolonged admission, the psychologist may have a useful role to play both in advising families on the child's staged return to school and liaising with schools in relation to this. In addition parents sometimes request specific advice on how to explain what has happened to the patient's siblings.

Another important aspect of the role of the paediatric psychologist in this setting relates to staff – both in terms of education and support – particularly given the high levels of burnout in this staff group (Embriaco et al., 2007). The presence of a psychologist in the multidisciplinary team has the potential to help other health professionals both directly, in the sense of relieving some of the emotional burden of

their work, and also indirectly, in terms of providing information and support which enables them to understand and manage their own emotional reactions, as well as those of the families of the children they care for.

Undertaking psychological research with this population

Despite the growing literature on the nature of the psychological impact on families of having a child in critical care, there is still very little good quality evidence on what works with this population, in terms of psychosocial intervention. The majority of interventions in intensive care settings address the often replicated findings that relatives and patients value proximity to their loved ones, reassurance and information and at this stressful time (Molter, 1979).

The provision of written information on the process of transfer to the general ward has been found to be associated with a reduction in parental anxiety in the short term (Bouvé et al., 1999) as has the availability of beds for parents on the unit (Smith et al., 2007). The literature on interventions directly with children is confined to case studies that have shown that distress can be reduced by providing appropriate play activities (Cataldo et al., 1979) or by bringing in a reminder of home such as a family pet (Vos et al., 2007). Another option is the 'COPE' intervention, which empowers parents to help their child make sense of what has happened to them through the use of a story book and a set of play materials, together with guidance on the range of reactions commonly seen after traumatic experiences. A randomised controlled trial has shown promising evidence of long-term positive outcomes in relation to both parental anxiety and the child's behaviour (Melnik et al., 2004).

There are, however, many challenges relating to carrying out research with this population. As, by definition, children on PICU are critically ill, it is usually not



Figure 2: From a story book made for a five-year-old boy following his treatment on PICU after bowel surgery, showing his visit to the laboratory where his artificial feed was made

possible to talk to them because they are either unconscious or heavily sedated. Furthermore, the majority are very young and a significant proportion of older children have communication problems related to their medical condition, making it difficult to obtain information directly from them.

Parents are highly anxious and so their ability to give informed consent at the point they are easiest to locate (i.e. when the child is on the unit) is clearly also an issue. They are understandably protective of their children and consequently not always prepared to involve them in research. In common with other traumatised groups in whom avoidant symptoms are common, they may also be ambivalent about discussing the psychological impact on themselves.

Future research in this area is necessary to determine whether two forms of intervention currently being trialled in adult intensive care settings – namely patient diaries and follow-up clinics – might usefully be adapted to paediatric patients and their families.

A patient diary in this context refers to

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a daily record of the patient's ICU stay, written in everyday language, usually by nursing staff at the bedside but with contributions from other health professionals and visiting family members. Content would usually include the reason for admission and details of significant events during the patient's stay on and off the ward: for example, extubation, the first time the patient managed to sit up, or an important family event, such as a birthday. The use of diaries with patients has been well received anecdotally, as they help to fill the 'memory gap' that many adult patients find disturbing (Griffiths & Jones, 2001). Furthermore, two recent randomised controlled trials have provided evidence that their use is associated with lower depression, anxiety and post-traumatic stress in adult ICU patients at follow-up (Jones et al., 2010; Knowles & Tarrier, 2009). To date, however, there have been no formal evaluations of diaries or story books with children, in terms of their impact on long-term distress.

Dedicated ICU follow-up clinics, at which issues specific to recovery after critical illness can be addressed, are growing in popularity (Griffiths et al., 2006), but to date have mainly been described in adult settings. The recent

NICE guideline on rehabilitation after intensive care has recommended that formal follow-up is offered more routinely, in order that the patient's physical and psychological recovery can be more closely monitored (NICE, 2009). However, it has yet to be clearly established in practice that such clinics are of benefit. The only large-scale randomised controlled trial that has evaluated the impact of a nurse-led follow-up clinic with a principal focus on physical rehabilitation found no evidence of psychological or physical benefit to patients at one year (Cuthbertson et al., 2009).

A pilot study in a paediatric setting found that the opportunity to attend an ICU follow-up clinic was associated with significantly lower rates of symptoms of parental depression and post-traumatic stress. This effect was, however, confined to parents who had been most distressed at the time of admission (Colville et al., 2010).

Conclusion

It is now an established fact that a significant minority of children and parents report levels of post-traumatic stress symptoms after a PICU admission that are both clinically significant and persistent. The potential sources of their

distress are multifactorial (Ward-Begnoche, 2007) but the fact that the child has required critical care treatment appears, in itself, to be a useful index of risk of later psychological problems for both patient and their caregivers. The NICE guideline on the treatment of post-traumatic stress disorder (NICE, 2005) has called for more research into screening populations such as these, who are at increased risk of being exposed to traumatic events, in order that interventions can be targeted at those who are most likely to benefit.

Paediatric psychologists are uniquely placed both to intervene clinically in the acute setting and to design and evaluate psychological interventions for this group. In doing so, they have the potential to reduce confusion and distress in the family and thereby facilitate the recovery and readjustment of the child.



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