

The Role of a Psychologist on the Paediatric Intensive Care Unit

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This paper highlights the many complex psychological needs of paediatric patients in intensive care. The literature on the experience of children in intensive care and their relatives is reviewed and related to the work of a paediatric psychologist. Case examples are given of direct work with children and suggestions are made of ways in which the psychologist can work in a consultation/liaison capacity. The personal impact of this work is addressed, as is the need to disseminate information to other health professionals. Further research is called for, both on the child's experience and on the development of appropriate psychological interventions.

Keywords: Paediatric psychology; PICU; traumatic stress; trauma; intensive care

Introduction

The Paediatric Intensive Care Unit (PICU) is, for many, the place where a family's life changes forever. There are many potential losses to be acknowledged aside from the obvious one of death, such as brain damage, personality change and disfigurement. It is here that parents may first learn of a child's diagnosis, sometimes with catastrophic implications for the rest of the family (as when a baby is found to be HIV positive). Initial relief that a child has survived a critical period may give way to new dilemmas such as increased dependency in the parent and child relationship. When a child is sent home on a ventilator there are major implications both for individual development and for the logistics of family life.

From a psychological point of view, on admission there is the immediate emotional impact of the child's physical and psychological distress upon the family to consider. Families may be at increased risk of developing subsequent post traumatic stress disorder (PTSD). The psychological problems experienced by parents and children in intensive care may be similar to those experienced in other paediatric settings, but they are more extreme and intense.

Lloyd (1993), a psychiatrist working in an adult intensive care setting, has called for a greater awareness of psychological distress in ICU patients, and the British Paediatric Association (1993) has recommended that the

special psychosocial needs of children on PICU be addressed. However, at the moment only 54% of units in the UK have an allocated social worker and fewer (31%) a psychologist, with 19% having no dedicated psychosocial staff on their team (Colville, 1998).

Paediatric intensive care

The age range of patients on PICU is 0–16 years, although newborn children would normally be admitted to dedicated neonatal units (also known as Special Care Baby Units). The current national shortage of PICU beds is such that children are also occasionally cared for on adult units.

By definition, care on PICU is intensive. The child has a nurse at the bedside 24 hours a day and much use is made of sophisticated technological equipment, both for monitoring vital signs and to support basic functions, such as breathing. Many admissions to PICU are acute and therefore unplanned, but a significant proportion are planned as part of post-operative care, particularly when it can be anticipated that the child will need close monitoring in the recovery period, for example following major abdominal surgery. Most such children are heavily sedated but not all are artificially ventilated: some are admitted as high dependency patients for close observation. The average length of stay is usually under 5 days, but medical advances in recent years have given rise to the increased survival of a number of long term ventilated children, who may spend several months on a unit. Mortality rates are, at 5–10%, relatively low as compared

with those of adult units, where approximately 20% of admissions result in death (Gunning & Rowan, 1999).

Acute admissions usually fall into one of the following categories:

- 1) accidental injury (e.g. road traffic accident, near drowning or inhalation or foreign body);
- 2) sudden acute illness (e.g. meningitis);
- 3) a deterioration in neurological condition;
- 4) respiratory distress (e.g. as part of the sequelae of prematurity);
- 5) children admitted for post-operative care.

In this paper the literature on psychological aspects of admission to intensive care is reviewed, and the nature of the work of a psychologist working in a liaison capacity on a paediatric unit is discussed. An outline is then provided of the main clinical issues likely to confront a psychologist in this setting, drawing on the direct clinical work of the writer—a paediatric psychologist based in a London teaching hospital who uses a primarily cognitive behavioural framework.

Literature review

The experience of patients within intensive care

Studies on the psychological aspects related to admission to an intensive care unit are contained mainly in the nursing literature. Here the focus has been predominantly on premature babies and their carers, rather than on child admissions. This has inevitably resulted in an emphasis on the parental experience of infant admission. Authors identify the aspects of admission found to be most stressful and most commonly associated with later adjustment difficulties as uncertainty about prognosis, length of stay and lack of social support (Raeside, 1997; Wereszczak, Miles, & Holditch-Davis, 1997 and DeMier et al., 1996). At the same time they question the need for professional help for the majority who cope remarkably well (Affleck, Tennen, & Rowe, 1991).

Given the limited amount of information available on what it is like to be a patient within an intensive care setting, two sets of literature dealing with this experience are reviewed. The first relates to what is known about the child's experience of intensive care. The second presents findings from the adult literature which highlights the distress experienced by adults who undergo procedures similar to those likely to be encountered by children in paediatric intensive care units.

The child's experience of intensive care: There are few accounts of the child's own experience of intensive care although Craft (1995) draws attention to the special psychological needs of these children. Distress in a conscious child during admission may present as marked lack of engagement or as more active resistance. The latter clearly 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 the patient, who is by definition already in a critical state. Ambuel et al. (1992) point out the limitations of many commonly used behavioural distress scales (which are primarily intended to measure acute pain in relation to discrete procedures) with this population. They have developed a useful observational scoring system for measuring psychological 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. Gavin and Roesler (1997) have described posttraumatic symptomatology in three children following airway intubation (for the purposes of artificial ventilation) and 'out of body' or 'near death' experiences have also been described in this population (Morse, 1994). The quality of sleep on intensive care is another issue that has been examined: on PICU, normal sleep stages are not seen and REM sleep is absent (Donnelly, Cullen, & Morrison, 1997).

The adult's experience of intensive care: Although anaesthetists recommend good sedation as a way to avoid the laying down of uncomfortable memories, there is research evidence that 64% of adults have some memory of their stay (White, Eddlestone, & Guthrie, 1997). Aspects of an admission to intensive care cited as most distressing from the adult patient's perspective, concern difficulties communicating and lack of control: patients find the inability to speak, with a ventilator in situ, isolating and frightening (Menzel, 1998). They are also often confused and disorientated, drifting in and out of consciousness, as a result both of illness and of sedation, and retrospectively report a need for ongoing information about their treatment and reassurance during admission (Hafsteindottir, 1996). Sometimes they appear so detached from what is going on around them that a phenomenon known as ICU syndrome is said to ensue (Granberg, Engberg, & Lundberg, 1996). Recent commentators regard this term as unhelpful however, arguing that it is more appropriate to conceptualise such behaviour as a form of delirium, resulting from a combination of organic causes and drug withdrawal (McGuire et al., 2000). Patients may experience acute anxiety associated with the fear of not being able to breathe, (particularly during the process of clearing the tracheotomy tube). There is also an inevitable sense of lack of control, no doubt compounded by the necessary occasional use of paralysing drugs. The repeated invasive procedures to which patients are subjected have been described by one author as akin to torture (Dyer, 1995).

Parents' and relatives' experience of intensive care: The environmental assault on the senses in intensive care units (referred to as 'sensoristain' by Black, Deeny and McKenna, 1997) has been assumed to contribute to relatives' distress. However, the principal finding of the work of Carter and Miles (1989), who developed a PICU specific questionnaire measure of parental stress was that

the main source of strain for parents was the disruption to their parental role. Carnevale (1990) makes similar observations and comments further on the way that this can lead to conflict between parents and staff.

With regard to later psychopathology in parents, Sumner et al. (1990) found significant levels of irritability and sleep disturbance in parents 3 months after discharge. Similar findings have led Gavin and Roesler (1997) to advocate the use of parent support groups after admission. Clinicians offering follow up clinics for adult ICU survivors also report a significant level of psychological morbidity in relatives after discharge (Waldman & Gaine, 1996).

Intervention with children

The procedures to which children are subjected whilst in intensive care can be, as the adult literature suggests, intensively painful. Thus, good pain control is essential (Southall et al., 1993). Where a child is conscious, some distress is unavoidable. It is, however, possible to manipulate the parameters of the child's experience in such a way as to minimise this. Cataldo et al. (1979), who found that one third of their sample of patients on PICU were 'conscious but markedly nonengaged', have shown that the introduction of age appropriate activities on the unit, increased positive affect and decreased inappropriate behaviours (such as self stimulation, in the form of finger sucking, 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. Gavin and Roesler (1997) comment on the value of play therapy involving reenactment of the traumatic experience after discharge; they report that this resulted in reduced anxiety in medical settings subsequently, and improvements in quality of sleep and social functioning.

Other literature relevant to promoting the child and family's wellbeing during admission includes the literature on stress and coping (Lazarus & Folkman, 1984), pediatric psychology (Roberts, 1996; New & Young, 1993), children's understanding of illness (Eiser, 1990; Rushforth, 1999), supporting families of sick children (Edwards & Davis, 1997), and post traumatic stress disorder. The latter literature is increasingly addressing medical situations, and provides further evidence of lasting distress in paediatric populations (Stallard, Velleman, & Baldwin, 1998; Walker et al., 1999; Aaron, Zaglul, & Emery, 1999). Another issue pertinent to work in acute settings such as PICU is the current debate about the value of debriefing (Wessely, Rose, & Bisson, 1999).

The role of the psychologist on PICU

Type of work

The work of a psychologist on PICU is similar in many respects to that undertaken on general inpatient wards,

but has to be adapted to fit the ICU context. In particular there is the environmental setting with its high reliance on technological monitoring and the serious limitations on the child's ability to communicate. There is also the context of highly complex ethical decision making regarding withdrawal of treatment and the extreme seriousness of the child's condition.

Clinical skills

The psychologist working on intensive care will need to employ a range of clinical skills including direct intervention with families and children, and liaison and consultation with other professionals. Given the range of medical problems presenting in PICU, liaison and consultation work is likely to involve almost every other paediatric speciality at one time or another. In terms of direct clinical work, the psychologist needs to be able to develop rapport quickly in a situation of high tension, frequently with no previous knowledge of the child or family. There is also the particular challenge of working with patients who are highly sedated, or unable to speak because of the ventilator tube.

Availability

It is important for psychologists to plan their schedule in such a way as to be available at short notice, in order to respond to what is often a rapidly changing clinical situation. At the same time their role needs to be clear so that unrealistic expectations are not created. Their level of involvement will vary to some extent with the availability of other psychosocial personnel (e.g. play therapists, social workers, liaison nurses). Usually, however, the constraints on the psychologist's time will be such that it is necessary to work in a consulting capacity with another member of staff, such as the bedside nurse, who will have more direct contact time with the child.

Professional issues

This work can be extremely draining emotionally. Frequent exposure to sudden death takes its toll and there is a danger of developing a distorted perception of personal risk, when one is confronted by deaths resulting from commonplace accidents, (such as falling down stairs or a routine dental anaesthetic). Good supervision and a balanced workload are clearly essential in this regard. Smith, Perrin, & Yule (1999) point out that it is just as important to attend to the needs of therapists in routine hospital settings as it is in major disasters, where the risks of burnout are more likely to be considered.

Working with the child

Pre-admission

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 the psychologist's future involvement. For example, past

negative associations with the intensive care environment may need to be taken into account in understanding the special significance of an admission, however routine from the staff's point of view.

During admission

The main reasons for referral to psychology during an admission centre around management of the child's distress, communication and occupation. A simple intervention can often be very effective (see Case 1).

Children with some awareness of their surroundings on PICU may well become fearful in anticipation of 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 to come near them. The well established principles of desensitisation and adapting interventions to take account of the child's interests apply, although their application may require some lateral thinking (see Case 2).

A child may be referred for being uncooperative (e.g., for spitting into the nurse's eye whenever she attempts suction of secretions from their tracheotomy). In such a case, it can be very helpful to reframe this behaviour as an expression of a need for control over a situation where the child feels overwhelmingly powerless.

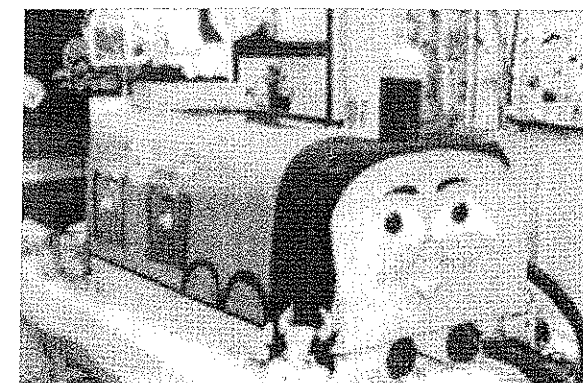
Children in PICU find it hard to find ways in which to occupy their time. This is particularly so when a child is on the unit for some time, as are those patients with high spinal lesions who are ventilator dependent. In contrast to other patients, these children may be fully conscious of what is going on around them and able to speak (when the ventilator tube has been connected directly to the airway, via a tracheotomy). 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 child to gain some control over their surroundings. The usual pastimes of listening to stories or musical tapes and watching videos may soothe and lift a child's mood in the short term, but in long admissions more varied materials should be offered, in the interests of the child's overall development and emotional wellbeing. A paraplegic child can derive all the usual pleasure afforded by doll play, if someone is on hand to follow their instructions. Also a child may feel a particular delight watching another messing around with paints, in this sterile, orderly environment.

Case examples

Case 1: preparation with an anxious child

A 3-year-old boy with an incurable muscle wasting condition was admitted from the local hospital following a deterioration in his condition. Attempts to wean him off the ventilator failed, and it was recommended that he be transferred to a negative pressure tank in order that he could spend his last few months at home with his family.

Figure 1. Negative pressure tank disguised as train



The child had demonstrated high levels of anxiety during admission, flushing bright red whenever staff approached, so the prospect of this transfer was a source of great apprehension. After some discussion it was decided that the tank should be disguised to look like Thomas the Tank Engine (the child's favourite story book character) and referred to as a special breathing train. The boy was given the opportunity to look at the train for some time before the scheduled transfer and when the time came, was very enthusiastic about it. Sadly, he died a month later at his local hospital.

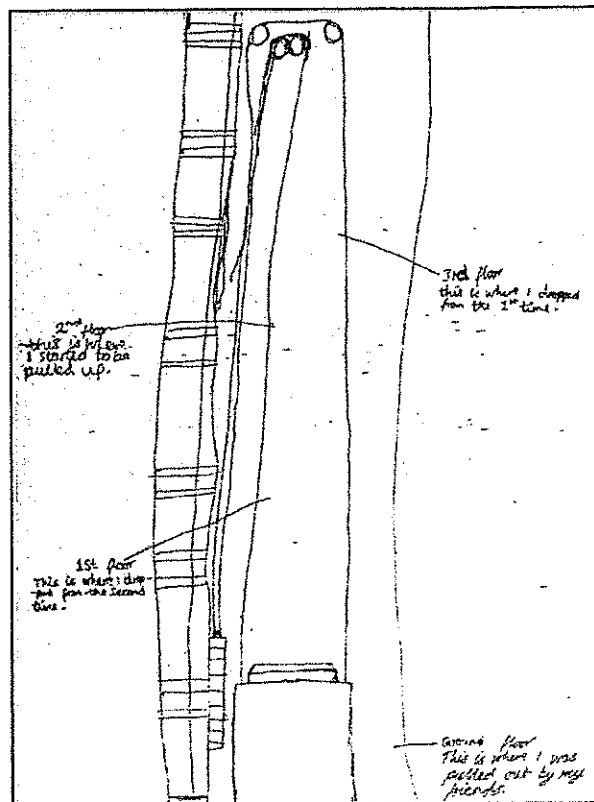
Case 2: communication difficulties in the recovery period

An 8-year-old girl had spent 4 weeks on PICU with acute peritonitis. After a period of medical instability, her condition began to improve and it was possible to wean her off the ventilator. As her sedation was reduced she was seen to become intermittently distressed and a referral was made to the psychologist for advice. Careful observation revealed that her distress was related to wetting herself before the nurse realised that she needed a bedpan. The child had been too weak to indicate her needs by gesture and too hoarse, after 4 weeks on a ventilator, to speak. The psychologist provided a dolls-house size toilet, which the girl was just able to raise discreetly, thereby avoiding her previous embarrassment, until such time as her voice and strength returned.

Case 3: PTSD development after discharge

A 13-year-old boy was referred after he reported having nightmares on the general ward following a serious fall in a lift shaft. His parents were provided with information about possible psychological symptoms and given details of how to contact the paediatric psychology service. They recontacted the psychologist after a month when the boy, despite having made a good physical recovery, found himself unable to return to school. Assessment of PTSD symptoms using the Impact of Events scale (Horowitz, Wilner, & Alvarez, 1979) showed very high levels of both intrusive thoughts and avoidant behaviours and his family reported high irritability and frequent temper outbursts. Although he was extremely reluctant to talk about the accident, he was able to write about it and draw diagrams to explain what had happened (see Fig. 2). After a series of

Figure 2. Child's drawing of site of accident



outpatient sessions, his symptom level decreased significantly. However he continued to have difficulties with school attendance and was consequently referred on to the local adolescent mental health service.

After transfer from PICU to the children's ward

It is often after transfer out of intensive care that the child's distress is most apparent. As the sedation wears off the child becomes more aware of pain and begins to try to make sense of what has happened. At this point he/she may experience nightmares and be uncharacteristically wary and fearful. The side effects of weaning off morphine may temporarily render the child's physical appearance very different (Hughes & Choonara, 1998), which can be quite upsetting for parents who may be anxiously seeking evidence that the child is returning to normal. Even if the child is not unduly distressed, there may be some value in making contact with the family, especially where the circumstances that gave rise to the admission were known to be traumatic. Information can be given both about normal reactions and how to seek further support (Troyna, 1988).

After discharge

Subsequent involvement may take the form of intervention with a focus on frank posttraumatic symptomatology, or help with newly acquired fears, particularly around further medical treatment. Older children sometimes appreciate being provided with a list of operations, giving names of procedures and dates performed, as they piece together details which are otherwise confused and

sketchy because of the amount of sedation or pain they experienced.

Working with parents and families

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 as an unwanted distraction. At this acute stage it is important to respect the parents' need to hold themselves together by whatever 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 provision of normalising information on how other parents have reported feeling in similar circumstances.

Referrals to the paediatric psychologist may come from a variety of sources, and it is as important within this field as in any other, to establish where the referral has come from, and why it has been made. In any referral the psychologist is likely to be working with a number of interacting systems, each of which will have its own characteristics and reasons for referral. For example, one reason for referral may be that the staff are finding a parent's behaviour difficult to handle. In this situation, discussion with the bedside nurse about management strategies or facilitating negotiations between parent and staff may be in order, particularly where there is evidence of a breakdown in communication. Alternatively, the referral may come from a parent distressed by perturbations in the family system. For example, there can be enormous tensions between parents if they have very different ways of handling the situation, or if one blames the other for what has happened. 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, of course, helpful if the psychologist can respond quickly, given the situation is often changing rapidly.

It is usual practice to offer a follow-up appointment with the consultant in the event of bereavement. These appointments provide an important opportunity to clear up misconceptions and, particularly if a psychosocial member of staff is in attendance, to check on the degree of distress and provide information on support services (Colville, 1993). In a recent UK survey (Colville, 1998) nearly half the units reported that they ran bereavement groups. The psychologist may decide to offer some individual bereavement support, but may not be best placed to offer long term work, particularly when, as is often the case, a family lives at a considerable distance from the unit. Fredman's (1998) recent reflections on the importance of establishing where the referral has originated from are also relevant here: staff may feel that a family would

benefit from a consultation but the family may see this as pathologising their grief, preferring instead to confide in friends and family.

Anecdotally, parents report feeling a need to talk about their experience some time after discharge from PICU but feel inhibited about recontacting the unit. In most centres a follow up appointment is sent in the event of a child's death, but it is not usual to provide an opportunity for a similar sort of debriefing if the child survives. The unique way in which PICU consultants operate, in that they take over clinical responsibility for the child's care on a temporary basis only, actually militates against this, since responsibility for follow up usually reverts back to a general paediatrician or GP. It is, however, becoming increasingly clear from the adult literature that an opportunity to speak again with ICU staff after discharge is very much appreciated by patients and relatives alike.

Parents sometimes present clinically, years later, claiming that the relationship with their child has altered irrevocably since admission. They may be aware that another child of the same age and with the same condition died and report something akin to survivor guilt, albeit by proxy, which is experienced as especially troubling. In common with patients described in the PTSD literature, 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, reporting increased consulting behaviour both in primary and secondary health care settings.

Working with PICU staff

The workload of staff on PICU is very demanding, both in terms of technical expertise and psychological resources. As Cataldo & Maldonado (1987) point out there is 'constant exposure to death, disfigurement, loss and dehumanisation'. It is hardly surprising then that the rates of staff illness and turnover tend to be higher in ICU nurses than in other nurses (Marshall & Kasman, 1980; Gentry & Parkes, 1982). Yet there is also evidence from research that the need for good teamwork in a crisis can work positively, with ICU nursing teams frequently reported as being particularly emotionally supportive (Maloney, 1982). Furthermore, job satisfaction in this area is not necessarily negatively correlated with stress (Rosenthal, Schmidt, & Black, 1989).

On occasion, the psychologist may be approached by an individual staff member for support with a case they may be finding difficult on a personal level. The need may also be identified for debriefing sessions in special situations. Colville's survey (1998) showed that half of the PICUs in the UK have regular staff support meetings. Other units reported preferring more informal support systems.

It is important to appreciate that, even where the psychologist is not providing formal staff input, their very presence in a team serves as a reminder that there is a

psychological dimension to care. Also, since staff are unlikely to have continuing involvement in most cases, they are grateful for feedback from a psychologist who is still in contact with a family after discharge.

Wider hospital role

In terms of the wider role of the psychologist in the ICU setting, organisational and communication skills are important. In this context Bennun (1999) stresses the value of a systemic approach and the need for mutual trust at all levels. There may be a need to mediate between relatives and managers in highly charged situations. A number of different departments (e.g. social services, legal department, mortuary, press office) may need to be kept informed about a rapidly changing situation. Admissions that attract press interest, either because of the family's celebrity or the significance of the accident, call for skills in diplomacy and teamwork. Strategy meetings are very useful in the management of longer term cases where there is multi-agency involvement.

Lastly, there is also clearly a role both for input into policy (e.g. on bereavement support) and involvement in research into the experience of patients and their families and the efficacy of different psychological interventions. There is currently a dearth of information on the child's experience and more work needs to be done to establish best practice in terms of the nature and timing of follow up offered.

Conclusions

The work of a psychologist on PICU is fascinating and varied but can also involve a bewilderingly rapid switch between feeling redundant one moment, and central to the most extreme of human dramas the next. The special demands and fluctuating needs on these units need to be addressed in terms of timetable, role definition and personal resources.

As regards future research, more first hand information on the child's experience is needed. Psychologists are, by virtue of their training and experience, particularly well placed to collect such information systematically, and then to plan appropriate interventions and evaluate them.

Much has been written in the last two decades about the effects of disaster on the human psyche. The central challenge here is to establish how best to work preventatively at the point when everyday medical disaster strikes.

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Occasional Papers No. 16

**Chronic Fatigue Syndrome:
Helping Children and Adolescents**

Edited by Elena Garralda

This Occasional Paper aims to bring together the experience of a number of clinicians working in child and adolescent mental health services who have been active in the management of children presenting with chronic fatigue syndrome. As well as including the presentations made at two ACPP meetings, it includes recommendations of current best practice, as debated and amended at those meetings. Contents include the following:

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