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; trauma stress; trauma; intensive care

Introduction

The Paediatric Intensive Care Unit (PICU) is, for many, the beginning of 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 see 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, admission to 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 severe 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 34% 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 at 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 of foreign body);
2) sudden acute illness (e.g. meningitis);
3) a deterioration in neurologic 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 study

The literature on psychological aspects related to admission to an intensive care unit is contained mainly in the nursing literature. Here the focus has been predominantly on premature babies and their careers, 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 (Ramsde, 1997; Wersetzen, Mikk, & Holmich-Dervuy, 1997 and DeMott et al., 1996). At the same time they question the need for professional help for the majority who cope remarkably well (Abbeck, 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 direct 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 be presented as marked lack of engagement or as nonactive 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. Ambühl 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 as a continuous observation. Gavin and Roesler (1997) have described posttraumatic symptomatology in children following airway intubation (for the purposes of artificial ventilation) and "out of body" and "in body" experiences have also been described in this population (Moss, 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 (Donnally, 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, Eddleston, & Guirre, 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 (Menzel, 1998). They are also often highly disoriented, 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 admiss (Henderson, 1966). Sometimes they appear so detached from what is going on around them that it is phenomenologically as an SCU syndrome is said to ensue (Granberg, Rosberg, & Lundberg, 1996). Recent commentators regard this term as unhelpful but, arguing that it is more appropriate to conceptualize such behaviour as a form of delirium, resulting from a combination of organic cause 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 tracheostomy tube. There is also an inevitable sense of lack of control, no doubt compounded by the necessary occasional use of paralyzing 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 'anomalous' by Black, Donn and McKern, 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. Carnovale (1996) 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, SUMMER et al. (1990) found significant levels of irritability and steep disturbance in parents 3 months after discharge. Similar findings have led Gavins and Ronset (1977) to advocate the use of parent support groups after admission. Clinicians offering follow-up clinics for adult ICU survivors should 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 units, as has been suggested, intensively painful. This 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. Catallo et al. (1979), who found that one third of their sample of patients on PICU were ‘conscious but markedly soondriven’, 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 you 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 overt distress in older patients; however, it was found to be of little value in therapy involving enroachment 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 school functioning.

Other literature relevant to promoting the child and family’s wellbeing during admissions includes the literature on stress and coping (Lazarus & Folkman, 1984), paediatric psychology (Roberts, 1996; New & Young, 1993), children in hospital (Eiser, 1990; Roeth, 1999), supporting families of sick children (Edwards & Davis, 1997), and treat trauma stress disorder. The latter literature is increasingly addressing medical situations, and provides further evidence of lasting distress in paediatric populations (Stallard, Veltman, & Baldwin, 1998; Walker et al., 1999; Aaron, Zegal, & Emyre, 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 clinical decision making regarding withdrawal of medical 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 encountered in ICU, liaison and case supervision is likely to involve almost every other paediatric specialty at some time or another. In the terms of the common 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 imperative 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 role 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 deaths takes its toll and there is a danger of developing a distorted perception of personal risk, where 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 the 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 lack of control over the contents 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 tracheostomy). In such a case, it may be very appropriate to use the unit 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 that they have control over such things as what is going on around them and able to speak (when the ventilator tube has been connected directly to the airway, via a tracheostomy). If available, the skill 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 moving around with paint in their shoe, in this sterile, orderly environment.

Case examples
Case 1: preparation with an anxious child
A 3-year-old boy with an inexcusable mumps warning 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, finding 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 a 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 disoriented 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, for 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 reconracted 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 significa-
cantly. 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 & Coonan, 1993), which can
be quite confusing 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
(Troyer, 1988).

After discharge
Subsequent involvement may take the form of inter-
vention with a focus on frank posttraumatic symptomolo-
gy, or help with newly acquired fears, particularly
around further medical treatment. Older children some-
times appreciate being provided with a list of operations,
giving names of procedures and dates performed, as they
piece together details which are otherwise confounded 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
without looking at the gory details of their child's current
condition. Contact may consist of little more than gentle
reminders to take breaks, sleep, eat, and an opportu-
nity to discuss the logistics of visiting arrangements.
There is also a fairly strong preference for 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 necessary, particularly where there is evidence
of a breakdown in communication. Alternatively, the
referral may come from a parent distressed by pertur-
bations in the family system. For example, there can be
erocious 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 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 appoint-
ments provide an important opportunity to clear up
misconceptions and, particularly if a psychological 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, 1999) nearly half
the units reported that they ran bereavement groups. The
psychologist may decide to offer some individual be-
reavement support, but may not be best placed to offer
long term work, particularly when, as is often the case, in
family lives at a considerable distance from the unit.
Fredrick'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 unusual to provide an opportunity for a
similar sort of debriefing if the child survives. The unique
way in which PICU consultations operate, in that they take
ever 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 to 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 irrevo-
cably 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 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 & Kaisan, 1980;
Gentry & Parkes, 1983). 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
(Rosenbalt, 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. The need may also be identified for
debriefing sessions in special situations. Colville's (1999)
survey showed that half of the PICU's in the UK have
regular staff support meetings. Other units reported
promoting 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 Bence (1999) stresses the
value of a systems 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 efforts.

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
needs and fluctuating needs on these units need to be
addressed in terms of timetable, role definitions 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 preventa-
tively at the point when everyday medical disaster strikes.

References
Psychology, 24, 335-343.
parents cope with newborn intensive care and its aftermath.
New York: Springer-Verlag.

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OCCASIONAL PAPERS No. 15

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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