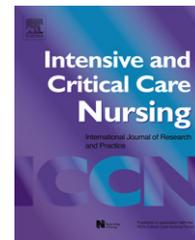




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ORIGINAL ARTICLE

The impact on parents of a child's admission to intensive care: Integration of qualitative findings from a cross-sectional study

Gillian Colville^{a,*}, Janet Darkins^b, Janet Hesketh^b,
Virginia Bennett^b, John Alcock^b, Jane Noyes^b

^a Paediatric Psychology Service, 2nd Floor Clare House, St George's Hospital, London SW17 0QT, United Kingdom

^b Centre for Health-Related Research, School of Healthcare Sciences, Bangor University, United Kingdom

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KEYWORDS

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Summary

Objectives: In this study, parents were asked which aspects of their experience of having a child in intensive care had caused them the most distress and how they continued to be affected by these experiences.

Research methodology: Semi-structured interviews held with 32 mothers and 18 fathers of children admitted to a paediatric intensive care unit 8 months earlier, were audiotaped, transcribed and subjected to a thematic analysis.

Setting: The setting was an eight-bed paediatric intensive care unit in an inner city teaching hospital.

Results: Significant themes included the vividness of parents' memories of admission; the intensity of distress associated with times of transition and the lasting impact of their experience, in terms both of the ongoing need to protect their child and in relation to their priorities in life. Fathers reported different coping strategies, spent less time on the unit and were less likely than mothers to report fearing that their child would die.

Conclusions: Parents report significant and persisting distress. Further research is needed on how best to support them acutely and in the longer term.

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Introduction

Research on parental stress relating to a child's critical illness has focused mainly on the immediate psychological impact on parents, while their child is in the paediatric intensive care unit (PICU), when their anxiety levels are 'elevated to near panic' (Shudy et al., 2006). Seminal studies have shown that parents are more distressed by the impact

* Corresponding author. Tel.: +44 208 725 2214;
fax: +44 208 725 2251.

E-mail address: gcolvill@sgul.ac.uk (G. Colville).

on their parental role, than by the unfamiliar, highly technological environment (Carter and Miles, 1989), and that their primary needs at this point are for proximity to the child and regular information (Molter, 1979; Fisher, 1994). Recognition of these needs has prompted a number of interventions (Smith et al., 2007; Linton et al., 2008).

Recently a small number of studies have reported on the *longer term* impacts of admission on parents, showing that levels of distress are raised for months after discharge (Board and Ryan-Wenger, 2003; Rees et al., 2004). One large-scale prospective study has demonstrated that parents' post-traumatic stress is related to their acute stress at the time of admission and their estimate of the threat to their child's life (Balluffi et al., 2004).

A number of authors have highlighted the need for more longitudinal research in this field, for more information on fathers' experiences and greater involvement of researchers from a variety of academic backgrounds (Board, 2004; Board and Ryan-Wenger, 2000; Noyes, 1998; Shudy et al., 2006).

Psychological reactions to traumatic stress

The literature on post-traumatic stress disorder (American Psychiatric Association, 1994) has grown substantially since the condition was first formally recognised in 1980. Ozer et al. (2003) report, in a comprehensive meta-analysis, that immediate psychological reactions at the time of trauma are stronger predictors of post-traumatic stress than prior personal characteristics but concede that the mechanisms by which a proportion of people develop chronic symptoms remain poorly understood.

Ehlers and Clark (2000), in their cognitive model of post-traumatic stress disorder, have stressed the value of asking individuals about the 'hotspots' in their traumatic experience as a way to uncover key cognitions at the time, since these influence how they make sense of what has happened to them. According to this model, two features of these early reactions associated with poorer outcome are (a) a persistent sense of threat and (b) avoidance of reminders of the trauma, leading to poor integration of traumatic events into autobiographical memory.

Aims of study

The qualitative data reported on in this paper were collected as part of a mixed-method study. The study was cross-sectional but had a longitudinal perspective, in that data was collected both on how parents were feeling at the time of interview and on their retrospective reflections on their psychological reactions at the time of admission.

The aims of the dominant *quantitative* component of this study were to establish rates of psychological distress in parents, 8 months after their child's discharge from PICU and to examine the associations between this distress and other variables (Colville et al., 2003a; Colville and Gracey, 2006).

The main aims of the nested *qualitative* component of the study, reported here, were to amplify on and explain the quantitative findings. Specifically it was hoped that the insights provided by the qualitative analysis of parents' comments would help to explain the high incidence of post-traumatic stress and anxiety in this group as a whole and

the relatively higher rates of distress reported by mothers. It was hypothesised that parents' narratives of their time on PICU would be characterised by descriptions of disturbing memories paired with powerful emotional reactions and that there would be systematic differences between mothers' and fathers' recollections.

Method

Design

In this cross-sectional mixed-method cohort study, we used a generic qualitative approach and adopted Caelli et al. (2003) criteria for establishing rigour: we made clear the *theoretical positioning* of the multi-disciplinary researcher team by putting forward hypotheses, and used qualitative and quantitative data to explore these assumptions.

Interviews were chosen as a means of obtaining parents' opinions, descriptions and often hidden interpretations of their own experiences in their own words. Parents were asked a series of open-ended questions about their experiences on PICU and how they continued to be affected by them. It was hoped that this approach would promote *congruence between methodology and methods* and enable understanding of the wider context of parents' adaptation to their experiences (Barbour, 1999). The Framework Approach (Ritchie and Spencer, 1995) was used as a *rigorous analytical lens* and concepts in the literature on parental stress and coping (LaMontagne et al., 1995; Lazarus, 1966) informed the examination of specific areas of interest raised by the quantitative findings.

Ethical approval for the study was obtained from the Local Research Ethics Committee.

Participants and context

The setting was an eight-bed PICU in a teaching hospital in London, UK. The sample was drawn from a cohort of families of children, consecutively admitted to the unit, for over 24 h, over an 8-month period. Families were excluded if the child had died or been readmitted to PICU.

Data collection

Parents were interviewed separately at home, 8 months after their child was in PICU by one of two interviewers, DG and GC, one of whom was male and one female. In the interests of maximizing recruitment, interviews were held in the evening and at the weekend if a parent was unable to make a daytime appointment because of work commitments. Before completing standardised questionnaires on their distress (for the quantitative component of the study, reported on elsewhere), parents were asked the following four open-ended questions:

1. What do you remember about the time X was on PICU?
2. What was the worst thing about PICU? Does any particular incident or time stand out in your memory?
3. How did you cope on PICU?

4. Do you feel the experience on PICU has changed you? If so, how?

Parents' responses to these questions were tape-recorded and transcribed verbatim.

Data analysis

Data were analysed thematically using the Framework Approach (Ritchie and Spencer, 1995) with the aid of the qualitative data software package NVivo2 (QSR International, 1999). Following initial reading, a coding framework was developed in an iterative way and applied to each transcript. Maps and charts were created to explore relationships and concepts. Concepts, constructs and explanations of mothers' and fathers' experiences were defined, described and mapped against the aims, research questions and specific areas of interest in the quantitative dataset. Transcripts were examined for deviant cases (examples of parental experiences that appeared to contradict the experiences of the majority), and where appropriate, reasons for difference examined in order to represent different parents' perspectives. In addition, transcripts of mother–father pairs were examined for evidence of systematic differences. Team meetings were an important aspect of the process so that coding, indexing, charting, mapping and interpretation could be compared and discussed.

Results

Recruitment

Of the families of the 105 children admitted in the study period, 10 could not be traced and four were excluded at a doctor's request, leaving 91 families contacted in all. No statistically significant demographic or medical differences were found between those who took part and those who did not, in terms of medical or demographic variables.

Fifty-two parents of 34 children agreed to take part, but two interview recordings failed, which meant that the final sample eligible for analysis consisted of 50 parents (17 mother–father pairs; 15 mothers and 1 father). Interviews were held a median of 7.7 months (range 5.7–12) after the child's discharge from PICU. Mothers were aged a median of 37 years (range 22–49) and fathers 38.5 years (range 29–46). In total 20/32 mothers and 17/18 fathers were in paid employment. Sample characteristics of the children are given in Table 1.

Main themes

The findings are reported below in terms of the following emergent themes: (a) vivid memories; (b) communication with staff; (c) transitions and (d) long-term impacts. Also, where appropriate, they are discussed in relation to the previously reported quantitative data. Quotes from transcripts are coded by a unique number allocated to each family and by the gender of the participant (mother=M; father=F). Themes and sub-themes are summarised in Table 2.

Table 1 Sample characteristics of children (n=34).

	Frequency n (%) or median (range)
Child age (years)	0.6 (0–15.1)
Male sex	15 (44%)
Length of stay on PICU (days)	4 (1–16)
Reason for admission:	
Medical emergency	24 (71%)
Surgical emergency	6 (18%)
Elective surgery	4 (12%)
Child ventilated	23 (68%)
Previously admitted to PICU	6 (18%)

Vivid memories

One of the most striking aspects of the interviews was the vividness of parents' memories, 8 months on. There was an almost magical quality to the comments describing parents' first impressions of PICU, indicating a mixture of relief at arriving, awe at the technology and a general sense of unreality in relation to what was happening to them and their child. One father described it '*like stepping into the 'Star Ship Enterprise!*' (099F), while another likened the unit to '*a little oasis*' (033F).

And yet, although they professed to having an '*enormous feeling of reassurance*' (021M) on arrival, the nature of other, more uncomfortable emotional reactions at key points in the admission also stood out in parents' memories. One example of a time that many could recall clearly was the moment they first received the child's diagnosis, which one mother described as follows: '*I just felt as though I'd been hit by a hammer*' (028M).

Parents' comments amplified the findings of the quantitative analysis, which showed high levels of stress associated particularly with witnessing medical procedures and the child's appearance. They found it unbearable, at times, watching what their child had to undergo: '*Every time*

Table 2 Main themes and sub-themes.

(1) Vivid memories of PICU
- first impressions
- moments of realisation
- witnessing procedures
- child's appearance
(2) Staff communication on PICU
- good communication
- humour
- communication problems
(3) Transitions
- anxiety pre-admission
- distress following transfer to ward
(4) Long-term impact of experience
- post-traumatic stress symptoms
- changes in relationship with child
- positive changes

they stuck the needle in, it was like they were just sticking...knives in me' (095M).

Parents recalled powerful haunting images of their child's appearance, which were often quite shocking, not only because of the number of pieces of equipment attached to the child's body, but also because of the oedema several children developed. One mother described her child thus: 'She was so bloated and she looked terrible. I just could not make myself go near her' (120M).

Parents also experienced extremely high levels of anxiety in relation to what they saw and heard on the unit, which were accompanied by dramatic physiological responses: 'When the alarms were going off...for the first three days...my heart just went berserk' (127M).

They were constantly aware of the proximity of death, both in terms of their own child's critical state and that of other patients around them. One father remembered: 'Standing there looking at her thinking she might be dead next week, that was what hurt; the rest did not matter' (008F). Another parent was struck by how different the outcome was going to be for other families: 'The horrible thing was that my little girl was getting better and ready to leave and his was getting worse...she was going to die' (030M).

In summary, when asked what they remembered about their time on PICU, parents recalled vivid, and often shocking, images of their child and a bewildering mixture of emotions. These included horror, fear, disorientation and impotence but also intense gratitude and relief.

Staff communication on PICU

Many of the parents' responses during the interviews concerned the way in which staff communicated and behaved with them. Parents' comments were overwhelmingly positive. Parents appreciated openness, patience and approachability in staff. Positive communication was described as follows: 'They were very good with us even when we asked silly questions' (008F).

Also, and perhaps surprisingly given the context of critical illness, there were numerous comments on the importance of humour: 'They talked to me as a person and as a human being...I was made to feel comfortable about laughing' (109M).

However, although many parents coped by placing their trust in the staff and talking to them, others found it difficult to talk, both at the time of the admission and since. One mother explained: 'We had to deal with it ourselves before we could talk to people' (021M) and another specifically mentioned her gratitude to staff for being sensitive to the fact there were times when she did not want to talk: 'All the staff were very good, if you wanted to talk you talked, if you didn't want to talk you didn't' (033M).

Although only a minority of parents rated staff communication as a major source of stress, those that did so reported higher rates of psychological distress at follow up. Examples of unsatisfactory interactions with staff, provided in the interviews, included inappropriate body language and poor timing, especially in relation to the delivery of bad news. Parents were also unhappy when staff forgot to introduce themselves and found it difficult when they were receiving inconsistent information: 'You do tend to get completely conflicting answers from two different doctors' (008F).

Finally, one of the hypotheses upheld by the quantitative data was that talking about the experience at the time would be associated with lower rates of distress at follow up. The qualitative data revealed that parents were more likely to confide in people they already knew, than in healthcare professionals. Friends and family outside the unit played an important role in helping parents cope by listening to their story, relieving them of other duties, and allowing them to focus on their sick child.

Transitions

Although the focus of the interview was intended to be the PICU experience, it was noteworthy how often parents raised the subject of their child's care outside the unit, preceding the admission and afterwards. In particular, parents' responses to the question asking what they considered to be the worst point often clustered around these two important stages of the child's journey. As one father put it: 'The difficulties were...before and after. PICU itself was fine' (021F).

Parents frequently described a powerful sense that there was something seriously wrong prior to the child's intensive care admission and that it was difficult to have these fears taken seriously by health professionals. One mother described herself as having a 'hysterical fit' (021M) when trying to gain the concern of a doctor at the local hospital. Another father said he 'nearly had to punch the doctor to get them to listen' (028F).

It had originally been hypothesised that the parents of children admitted to PICU at short notice would be the most upset at follow up, but in fact the quantitative data showed that levels of distress were highest in parents whose child had taken over 24h to reach the unit. Examination of the transcripts from parents whose child had taken longer to get to intensive care, revealed that they were more likely to report that their initial concerns had not been taken seriously at the local hospital or by their General Practitioner.

The anxiety parents felt on the journey from the local hospital to PICU was also recounted graphically. One mother recalled: 'I thought she was dying in the back of the car with me...the journey to the hospital was probably the worst 12 minutes of my life' (095M).

The other major transition parents mentioned, was the child's discharge to the general ward. Although parents recognised that the fact that their child was well enough to be transferred out of PICU was a positive development, they found this change very stressful and were emotionally unprepared, particularly for the reduction in staffing ratios. The following narrative by a mother is representative of the concerns experienced by many parents in the sample: 'There was no 24 hours nurse, which was the biggest thing which upset me... The poor nurse who received us had to deal with me more than [my child]... it was awful, it was like living in a refugee camp' (104M). Another described the ward as 'planets apart' (021M) from PICU.

The main source of stress for parents immediately before and after PICU admission was their fear for the child's immediate safety, but their anxiety was compounded by the bewilderment they felt at the changes of staff and surroundings and a sense of abandonment on transfer to the general ward, which they described in dramatic terms and seemed

to be related to the loss of intense relationships forged with staff on PICU, even when the admission had been relatively short. Parents described being '*spat out*' (109M) and '*shunted upstairs*' (083F). One father explained '*You interact with them very intensively over a short period and then you never see them again*' (008F).

In summary, it was clear from these interviews that, in order to understand fully the experiences of these parents, it was important to acknowledge that the PICU admission was only part of their narrative, and that there was a wider context to their experience. Indeed for several parents it was the traumatic events just before or just after the admission, which stood out, on reflection, as the most distressing.

Long-term impacts

All but eight parents felt that either they, or their relationship with their child, had been changed by their experiences on PICU. They described a sense of unreality about what had happened: '*Sometimes I still look at her and think "Did it happen? Was it a dream?", like I was someone else*' (120M).

Other parents identified sensory experiences in the present, which brought back distressing memories of the admission. One father found it difficult going to the dentist: '*I can't stand to hear suction because that floods it back quicker than anything*' (028F). A mother felt frightened at work '*every time the phone rings and they say it's for me*' (081M).

Parents also gave examples of avoidant behaviour. One mother could not even bear to catch sight of the hospital when she passed it: '*The thought of passing (the hospital) – I can't, I don't look at that side. If I go to (that part of town) I don't look on the left*' (120M).

Many parents reported that they remained more anxious than before about their child's health. They acknowledged that they were more overprotective and were clear in their own minds that this change was the direct result of encountering their child's critical illness. They worried about their children coming to harm and checked them much more often than before. One mother explained: '*I just feel my whole life revolves around just making sure (child) is OK*' (030M).

Surprisingly however, in spite of their persisting distress, many parents simultaneously reported positive changes within themselves. They reported feeling that they had gained from the experience, for example in the sense of becoming more assertive, even though they would not have chosen to go through it. Typical responses included: '*I wouldn't wish it on anyone. . .but there are certainly aspects of the experience that I will see as positive and I will treasure*' (118F).

For some parents the experience had brought their family closer. For others, the change they described was of a more fundamental, philosophical nature and involved the development of a new perspective on life which entailed a reprioritisation of their core values: '*All the money in the world wouldn't have helped my daughter and so I have got no value on money, possessions now, just health*' (028F).

In summary, parents reported being profoundly affected by the experience of having a critically ill child and continued to be more concerned about their child's health than before. Their assessment of the long-term impact of their experience was not, however, wholly negative. On a personal level, parents were proud of themselves for meeting

the challenges they had faced and were impressed with the professionalism and dedication they encountered in the staff members caring for their child. Finally, although many of their memories were painful, the majority were grateful for the new outlook on life this experience had provided them.

Differences between mothers and fathers

The fact that the sample included 17 mother–father pairs provided an opportunity to examine differences between mothers' and fathers' experiences of the same traumatic event. The quantitative data indicated that mothers reported significantly higher rates of stress associated with the admission and of post-traumatic stress, 8 months later.

Coping styles

Parents often acknowledged that they coped in different ways. Sometimes these differences were described as complementary and seen positively in terms of what they could offer their child as a couple: '*If I was asking enough questions it meant she could be more emotionally involved with (child) rather than having to think so much about the questions*' (083F). For other couples, however, these differences could be a source of tension, during the admission and subsequently: '*She likes to talk about it and that's caused tension between us*' (089F).

There were examples of men adopting traditionally male coping strategies such as information seeking and focusing on practical rather than emotional things. Fathers described '*being in control and getting information*' (008F); '*being Mr Macho, being strong*' (083F) and '*being very focused*' (091F). They were more likely to use prioritising and making lists as coping strategies. They were also more likely to speak in terms of having to be strong for others and less likely to mention talking and getting involved in practical aspects of the child's care on the unit.

Exposure

Although both mothers and fathers mentioned the importance of focusing on the child, mothers were more likely to describe a need to be with their child as much as possible, although this often meant that they were exposed to more traumatic material, both in terms of what was happening to their own child and witnessing other life threatening events on the unit: '*He didn't go through as much as I went through because I was there all the time*' (108M).

Perception of threat

As a group, mothers were more likely than fathers to mention explicitly the possibility that their child could have died. Furthermore, more fathers than mothers explicitly stated that they did *not* consider that there was a risk of death, at any stage. The following pair of quotes, from the mother and father of the same child, illustrates just how differently two members of the same couple were sometimes construing the same events: '*At no time did I think it was life threatening.*' (014F); '*I was convinced she wasn't going to make it through the surgery.*' (014M).

In summary, analysis of the transcripts of couples revealed that mothers used different coping strategies to fathers, which included staying on PICU for longer, and were

more likely to believe that their child could die during admission.

Discussion

These qualitative findings complement and expand on the quantitative outcomes already reported on this sample. Parents described intense levels of stress associated with their child's admission and retained vivid memories of their experiences, many months later, echoing previous research on mothers, years after their child's neonatal intensive care admission (Wereszczak et al., 1997). The PICU experience was hard to process, emotionally and intellectually, because of the speed of the child's deterioration, the number of people involved in their care and the unpredictability of their medical course. The fact that parents spontaneously reported so many post-traumatic stress symptoms before these were formally assessed by questionnaire is evidence of the salience of this concept in this population. The fate of other patients acted as a constant reminder of the possibility of worse medical outcomes and the transfer to the general ward renewed anxiety about their child's safety. These aspects of parents' experience combined to produce an ongoing sense of threat, which is regarded as critical to the maintenance of post-traumatic stress symptoms in the longer term. The intense emotional and physiological reactions described, particularly in relation to their memories of the 'worst thing' that happened on PICU, also made it more likely that their memories of PICU would be re-experienced later in the form of flashbacks or nightmares (Ehlers and Clark, 2000). Furthermore, many parents felt that their experiences had made them hypervigilant and that this could be affecting their current relationship with their child. The phenomenon of parents continuing to worry about the health of their child after a period of critical illness has been recognised by paediatricians (Green and Solnit, 1964) and has been noted in another qualitative study with this population (Diaz-Caneja et al., 2005).

Parents' comments also provided insights into possible explanations for the higher rates of distress in mothers. In particular mothers appeared to get more involved in the day-to-day care of the child and spent longer periods of time on PICU. Their relatively higher rate of exposure to traumatic material, relating to their own child and other patients, could explain their higher rates of fear that the child would die and subsequent higher levels of post-traumatic stress. This hypothesis would be consistent with the work of Balluffi et al. (2004), who found that a parent's subjective perception of their child's risk of death was a strong predictor of their post-traumatic stress score at follow up.

Although it was evident from the transcripts that parents' were generally very positive about the quality of care they received on PICU, many found the transitions to and from intensive care particularly difficult emotionally. This aspect of their experience was not covered explicitly in the quantitative analyses but emerged as very significant during the interviews and was often recalled as the most stressful. Anxiety associated with the journey to PICU and with ward transfer has been noted before (Colville et al., 2003b; Cutler and Garner, 1995; Leith, 1998), but the fact that many parents in this study rated these aspects of their experience as

the worst 8 months later is an important finding which highlights the need for clinicians and researchers to focus more attention on these stages in the family's experience.

The importance of good communication with relatives in critical care settings, whereby definition the patient usually cannot communicate, has been stressed both in recent guidelines (Davidson et al., 2007) and in the special situation of end of life care on PICU (Meyer et al., 2006). The findings of this study suggest that, as Board (2004) has commented recently, much of the existing research identifying the need to improve communication with parents has been absorbed into routine practice, but they should not be grounds for complacency. Parents in this study who reported problems with communication also reported higher rates of psychological distress at follow up.

Parents' comments on the importance of humour are consistent with observations that this aspect of communication helps alleviate anxiety, aids coping and promotes self-expression in medical settings (Åstedt-Kurki et al., 2001). It could also be that the use of humour by staff was welcomed because it was interpreted as a sign that the child was out of danger.

Finally, an aspect of the parents' experience that only came to light once the qualitative data had been examined, was the phenomenon of positive change. This included improved relationships with family and friends, a new perspective on what was important in life and a greater recognition of parents' ability to cope. These findings are consistent with those of other authors, who have demonstrated, in a number of different populations, that struggling with adversity can produce a form of positive personal change, sometimes referred to as 'post-traumatic growth' (Linley and Joseph, 2004).

Strengths and limitations

This was a cross-sectional, retrospective study and as such inferior methodologically to a prospective study. However its longitudinal perspective marks it out from much of the research in this area and the qualitative analyses revealed important aspects of parents' experience that were not apparent in the quantitative analyses. Mixed-method approaches are increasingly advocated in health services research for just this purpose (Adamson et al., 2004). Particular strengths of this study were the size of the sample, which is large for a qualitative study, and the inclusion of fathers, whose experiences are often neglected in paediatrics (Phares et al., 2005). Efforts to maximize the recruitment of fathers included the appointment of a male interviewer and the flexibility of the timing of interviews. Finally, a major limitation of the study was the exclusion of families whose child died or child was readmitted to PICU.

Clinical implications

These data indicate that parents are in need of more support, particularly around the time of transfer to the ward (Mitchell et al., 2003). Formal psychosocial intervention is also required for those parents who go on to develop chronic psychological problems, such as post-traumatic stress, anxiety and depression. Current identification of parents with

persistent distress is however somewhat haphazard. This problem could be addressed by routine monitoring of parents' psychological well-being in follow up clinics such as those provided in adult settings (Griffiths et al., 2006).

Recommendations for further research

More research is needed on ways to screen parents for risk of long-term distress (Colville, 2006) in order that resources are targeted appropriately (NICE, 2005). In addition, future studies could establish the degree to which mothers' higher rates of stress are mediated by coping strategies, exposure to traumatic incidents and perceived degree of life threat to the child.

There is also a need for further development and evaluation of interventions with parents in this situation, both acutely and in the longer term. The extent of distress reported in this study in relation to the experience of transfer, suggests that interventions designed to promote parental coping around discharge could impact on parents' longer term psychological adjustment. The provision of written information to parents about ward transfer has been associated with reduced *short-term* anxiety (Bouve et al., 1999), as has the application of a dedicated transfer protocol (Van Waning et al., 2005). Future research on the effectiveness of measures such as these could also examine their *longer term* impacts on parents' psychological well-being.

Finally, the administration of a standardised measure of post-traumatic growth (such as the Posttraumatic Growth Inventory (Tedeschi and Calhoun, 1996)) to this population would establish the prevalence of this phenomenon more systematically.

Conclusion

Clearly the removal of all stress from parents in this situation is an unattainable aim. The suffering and potential loss of a child will inevitably generate intense anxiety in their parents. Nevertheless, by acquiring a clearer understanding of parents' experiences, health professionals will be better placed to make evidence based decisions about the care of families on and after PICU, which will ultimately promote the child's physical and psychological recovery.

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