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ORIGINAL ARTICLE

# Mothers' recollections of the Paediatric Intensive Care Unit: Associations with psychopathology and views on follow up

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## KEYWORDS

Posttraumatic stress;  
Intensive care;  
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**Summary** The aim of this study was to establish rates of posttraumatic stress symptoms in mothers after a child's admission to a Paediatric Intensive Care Unit (PICU) and their views on the potential value of a follow up appointment with PICU staff. Thirty-four mothers completed the Parental Stressor Scale:PICU, the General Health Questionnaire (GHQ-28) and the Impact of Event Scale, 8 months after discharge. In total 18/34 (53%) scored  $\geq 5$  on the GHQ-28 and 6/32 (18%) of the sample scored in the severe range ( $>35$ ) on the Impact of Event Scale. Distress was associated with retrospective reports of stress experienced during admission ( $p < 0.001$ ) but not with other demographic or medical variables. Mothers who talked about their feelings at the time of the admission had lower posttraumatic stress scores at 8 months ( $p = 0.02$ ) and 25/34 (74%) mothers would have appreciated the offer of a follow up appointment. Screening for distress during admission with the Parental Stressor Scale:PICU may identify those mothers in greatest need of psychological support.

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## Introduction

In the recent literature on traumatic stress, there has been increasing recognition of the impact of trauma on witnesses, where the threat to life or integrity of a loved one is sufficient to qualify

as a traumatic event. The relatives of patients admitted to Intensive Care Units frequently witness such events and are therefore theoretically at risk of developing psychological adjustment problems, including posttraumatic stress disorder (PTSD) (American Psychiatric Association, 1994). The more we can learn about the distress of these relatives, the greater chance we have of developing appropriate support services for them. In doing so, we will indirectly improve the care of patients,

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who rely heavily on relatives both in terms of understanding their medical condition and for daily care during their recovery.

In the adult critical care literature there is evidence that, during admission, significant numbers of relatives suffer symptoms of anxiety and depression (Pochard et al., 2001), but there is no information on how long these symptoms persist after discharge. Also, although higher levels of anxiety are reported in relatives with lower rates of contact with medical staff, and as many as half have problems understanding the patient's diagnosis (Azoulay et al., 2000), there is a lack of information on the effectiveness of interventions designed to tackle communication problems. Nevertheless, there are promising reports that follow up clinics (Waldmann, 1998; Hall-Smith et al., 1997) and diaries (Backman and Walther, 2001) are well received by patients and relatives alike and that individual units are experimenting with strategies to improve communication, such the provision of a family conference once a patient has been on artificial ventilation for 5 days (Dowd et al., 1998).

In a comprehensive review of studies of mothers' experiences and needs on the Paediatric Intensive Care Unit (PICU), Noyes (1998) found that these were predominantly North American, written from a nursing perspective and focused on the immediate impact of admission. A number of studies in this review use the Parental Stressor Scale:PICU (Carter and Miles, 1989) and consistently report that stress relating to impact on parent's role is higher than that relating to staff behaviour or environmental factors, with mothers exhibiting higher levels of stress than fathers (Riddle et al., 1989). Youngblut and Lauzon (1995) identify the following areas as giving rise to the highest levels of concern: the child's survival; the possibility of brain damage; seeing the child in pain and the diagnosis. The dearth of longitudinal data in this area to date has been disappointing, but three recent studies suggest that parental distress persists for many months after a child's admission to PICU (Balluffi et al., 2004), and that prevalence rates are higher than those seen after admission to a general paediatric ward (Board and Ryan-Wenger, 2003; Rees et al., 2004).

In recognition of the psychological impact of admission on patients and their families, recent UK government guidelines relating specifically to Critical Care (Department of Health, 2000), have highlighted the need for more research into the experiences of patients and carers. The Audit Commission (1999) have also recommended that services routinely provide follow up clinic care, but as yet there

are no published accounts of this type of provision in a paediatric setting.

In summary, although there is an extensive literature on the nature and degree of distress experienced by mothers on PICU, few studies make use of standardised measures of psychopathology, making comparison with other traumatised groups difficult, and follow up data is largely confined to the short term aftermath of admission only. Furthermore, although an increasing number of adult intensive care units are now offering follow up appointments, the level of demand for such services in families of paediatric intensive care survivors is unknown.

## Aims of study

The aims of this exploratory study were as follows: (1) to ascertain the extent of psychological distress, including posttraumatic stress, in mothers following their child's admission to PICU; (2) to identify which factors related to admission are associated with higher rates of distress; (3) to seek the views of mothers on the potential value of a follow up appointment with PICU staff.

It was hypothesised that mothers whose children were objectively more seriously ill, would be more traumatised at follow up, and that the degree of psychological distress directly associated with the admission would be positively correlated with psychopathology. It was further hypothesised that mothers who had talked about their experiences at the time, would be less distressed at follow up than those who had not, as they would have been more likely to have processed the traumatic event emotionally (Janoff-Bulman, 1989).

## Method

### Participants

The sample was drawn from a cohort of families of 105 survivors consecutively admitted to PICU for a minimum of 24 h, and not subsequently readmitted within the study period. In total, ten children were excluded because they could not be traced, and four because a doctor felt it was inappropriate to contact the family. Thus 91 families were invited to take part in the research.

### Design

This was a retrospective cross-sectional cohort study. Mothers were interviewed individually at home, using a semi structured interview and were,

in addition, asked to complete three self report questionnaires.

## Procedure

Approval was obtained from the local ethics committee for the project, on condition that families were only contacted once, by post. Participants received an information sheet and completed a written consent form. Interviews were held at home and lasted approximately 1.5 h.

## Measures

During the semi-structured interviews information was sought on demographic factors and on the child's previous health, as well as on what mothers remembered about the admission, how they had felt and coped and specifically whether or not they had talked to others about their experiences and feelings at the time.<sup>1</sup>

Mothers were then asked to complete the Parental Stressor Scale:PICU (Carter and Miles, 1989) retrospectively. This is a 36 item Likert scale questionnaire which measures parents' perception of PICU associated stress on seven different dimensions: child's appearance; sights and sounds; procedures; staff behaviour; staff communication; parental role and child's behaviour. Items on each scale are rated 1 (not stressful) to 5 (extremely stressful), with each subscale score being the mean of items scores and the total score being the mean of the seven subscale scores. The authors report alpha coefficients of 0.95 for the total instrument, and between 0.72 and 0.99 for the individual subscales.

The Impact of Event Scale (IES) (Horowitz et al., 1979) was also administered during the interview. This is a widely used, 15 item self-report measure of specific responses to trauma and was scored '0, 1, 3, 5', where '0' = 'not at all' and '5' = 'often'. Scores of over 35 are regarded as suggestive of a high risk of PTSD (Neal et al., 1994). The developers of the IES report satisfactory levels of reliability (0.86 split half and 0.87 test re-test) and internal consistency (Cronbach's alpha of 0.78).

The 28 item version of the General Health Questionnaire (GHQ-28) is a well established psychiatric screening questionnaire (Goldberg & Hillier, 1979). Items were scored using the GHQ scoring method ('0, 0, 1, 1') with scores of 5 and above regarded

as suggestive of high risk of future psychiatric disorder, such as depression.

## Analyses

As the sample size was relatively small and not all variables were normally distributed, descriptive data is presented in the form of median (inter-quartile range) and non-parametric statistics were employed to examine the relationships between the variables of interest. The Mann-Whitney *U*-test was used to examine differences between groups, where the dependent variable was continuous, and the Pearson  $\chi^2$ -test was used where the dependent variable was categorical. Spearman correlations were used to examine associations between continuous variables.

## Results

In total 34 mothers (33%) agreed to take part in the project.<sup>2</sup> There were no significant differences between the children of those who took part and those who did not, in terms of age; sex; length of admission; home distance from hospital or ventilation status. Interviews took place at a median follow up of 7.8 (7.0, 9.0) months after discharge from PICU. Sample characteristics are given in Table 1.

## Psychological outcome

Median score on the GHQ-28 was 5 (1, 10), with 53% of the sample scoring at or above the cut off of 5. Median IES score for mothers was 13 (2, 28). In total, 6/32 (18%) of mothers scored above the cut off of 35, suggesting they were at high risk of fulfilling the diagnostic criteria for post-traumatic stress disorder. During the interviews, mothers described how vividly they still remembered their child's admission: "I can't stand to hear suction at the dentist because that makes it flood back quicker than anything. I can see the images. I can replay it. It is like watching a black and white film where they have no sound." and how difficult it was to return to normal: "I'm frightened every time the phone rings at work and they say it's for me." There was no association, in this sample, between the length of time since admission and mother's psychological distress, on either outcome measure.

<sup>1</sup> A number of direct quotes are included in this paper in order to illustrate the main quantitative findings. Themes elicited during the interviews, which were all transcribed, are currently being analysed qualitatively and will be reported on separately.

<sup>2</sup> In addition, 18 fathers agreed to be interviewed. Analyses relating to the data for mother-father pairs are reported elsewhere (Colville et al., 2003).

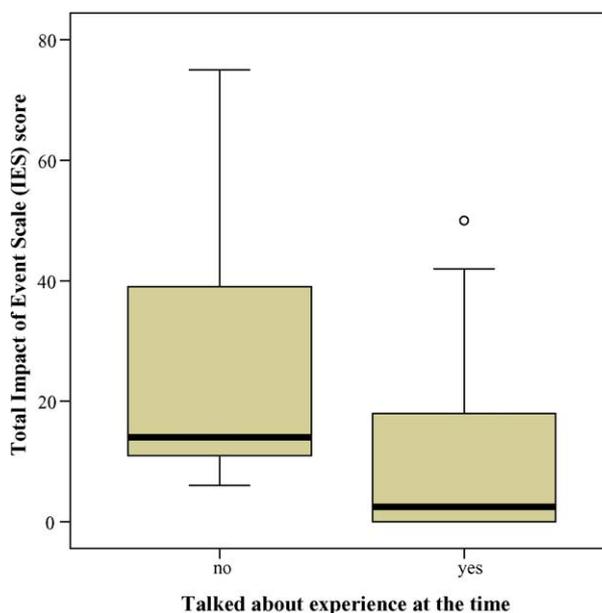
**Table 1** Sample characteristics ( $n = 34$ ).

	Median (inter-quartile range)
Mother's age (years)	37 (32.3, 38.8)
Age of child (years)	0.6 (0.2, 4.9)
No. of days on PICU	4 (2, 7)
	<i>N</i> (%)
Sex of child	
Male	15 (44)
Female	19 (56)
Referral category	
Respiratory	13 (38)
Post operative monitoring	7 (21)
Meningitis	5 (15)
Trauma	3 (9)
Other	3 (9)
Ventilation status	
Ventilated	23 (68)
High dependency	11 (32)
Previously admitted to ICU	6 (18)
Previously admitted to hospital	16 (47)
Length of time unwell before admission <sup>a</sup>	
<24 h	13 (43)
>24 h	17 (57)

<sup>a</sup> Excluding four elective admissions.

### Associations between main independent variables and psychological outcome

The only statistically significant association between medical or demographic variables and psychological outcome, related to the length of time the child had been unwell immediately prior to admission, in that mothers of children who had been ill for longer than 24 h before admission had higher GHQ-28 scores than those whose children



**Figure 1** Boxplots (indicating median and inter-quartile range) showing Impact of Event Scale score by whether or not mother reported that she had talked about her experiences at the time of admission.

were admitted more promptly (median 1 versus median 5, Mann–Whitney  $p = 0.01$ ). However, the correlations with the measure of PICU related stress (PSS:PICU) were highly significant for both outcome measures ( $r = 0.58$  for IES,  $p = 0.001$ ;  $r = 0.44$  for GHQ-28,  $p = 0.009$ ). In addition, as illustrated in Fig. 1, mothers who reported that they had talked to others about their feelings at the time of admission, had significantly lower scores on IES than those who did not (median 3 versus median 14, Mann–Whitney  $p = 0.02$ ).

Examination of the relationships between both the total score and the individual subscales of the PSS:PICU (Table 2) revealed that specific aspects of

**Table 2** Spearman's correlations between individual subscale scores on the Parental Stressor Scale:PICU (PSS:PICU) and scores on the Impact of Event Scale (IES) and the General Health Questionnaire (GHQ-28).

PSS:PICU ( $n = 34$ )			Spearman correlation with IES ( $n = 32$ ), $p$	Spearman correlation with GHQ-28 ( $n = 34$ ), $p$
Subscales <sup>a</sup>	Median score	% Scoring at least one item $\geq 4$		
Child's appearance	3.0	30	<b>0.05</b>	ns
Sights and sounds	3.0	62	<b>0.00</b>	ns
Procedures	3.2	59	<b>0.00</b>	<b>0.00</b>
Parent's role	3.3	47	ns	ns
Child's behaviour	3.0	38	ns	ns
Staff behaviour	1.0	6	ns	ns
Staff communication	2.3	33	ns	<b>0.00</b>

Associations reaching statistical significance at  $p < 0.05$  are indicated in bold type.

<sup>a</sup> Rated 1 (not stressful) to 5 (extremely stressful).

**Table 3** Sample characteristics associated with the desire for follow up.

	Mothers who wanted follow up ( <i>n</i> = 25)	Mothers who did not want follow up ( <i>n</i> = 9)	Test for heterogeneity (Mann–Whitney/Fisher Exact) <sup>a</sup>
	Median or %	Median or %	<i>p</i>
<b>Demographics</b>			
Age of mother (years)	38.0	32.5	<b>0.02</b>
Age of child (years)	1.0	0.3	<b>0.05</b>
% Male child	48%	33%	ns
<b>Health variables</b>			
% Previously admitted	44%	56%	ns
% Unwell <24 h	43%	43%	ns
<b>Admission variables</b>			
Length of PICU stay (days)	4	4	ns
% Ventilated	72%	56%	ns
<b>Coping</b>			
% Mothers talked at time	54%	78%	ns
<b>Stress related to admission</b>			
Parental Stressor Scale:PICU score	3.1	2.3	<b>0.04</b>
<b>Psychological outcome</b>			
Impact of Events Scale score	17	4	ns
General Health Questionnaire score	5	3	ns

Associations reaching statistical significance at  $p < 0.05$  are indicated in bold type.

<sup>a</sup> Median scores and Mann–Whitney  $p$  values are reported for continuous variables; sample proportions, expressed as percentage, and Fisher Exact  $p$  values are reported for categorical variables.

admission, albeit recalled retrospectively, were differentially related to psychological outcome. Stress associated with witnessing the child undergoing medical procedures (such as suctioning and insertion of lines) was significantly associated with both outcome measures, and stress relating both to the child's appearance and to the 'sights and sounds' on the unit, was significantly associated with the number of posttraumatic stress symptoms endorsed on the IES. Mothers were overwhelmingly complimentary about the way staff behaved on the unit, with only a very small minority reporting significant levels of stress associated with this aspect of their experience. However when there were communication difficulties with staff, although these were relatively low in frequency, there was an association with higher GHQ-28 scores.

These findings were further illustrated by mothers' comments during the interviews. One mother explained how distressing it was to witness her child undergoing essential procedures: "Every time they stuck the needle in, it was like they were sticking knives in me". Another explained how shocked she was at the change in her child's appearance: "She was so bloated and she looked terrible. I just could not make myself go near her. She was covered in wires and tubes going everywhere in her body"

### Views on provision of follow up

The majority of mothers, 25/34 (74%), reported that they would have appreciated a chance to meet with the PICU team again following discharge. In the interviews they indicated they felt they would have been grateful for a chance to discuss the admission once the child had recovered "I would have liked a follow up to talk through what happened" and believed that this might have been of benefit to them psychologically: "Maybe if you sit down and discuss it with somebody on a professional level sooner, you don't constantly think about it". Furthermore, 18/34 mothers (53%) would have appreciated a chance to speak to other parents who had been through a similar experience.

As can be seen in Table 3, there were few systematic differences between mothers who wanted follow up and those who did not. Specifically there was no association with severity of the child's illness, as indicated by length of stay or ventilation status, in this sample. However, those who reported higher levels of stress during admission, retrospectively on the PSS:PICU, were significantly more likely to state that they would have liked a follow up appointment. The association between IES score and desire for follow up was in a similar direction,

but narrowly missed significance. There was also a tendency for mothers (and consequently children) who were older, to want follow up.

## Discussion

This exploratory study provides psychological outcome data on the mothers of paediatric critical care patients. In total 18% of the sample exhibited clinically significant levels of posttraumatic stress, and 53% reported significant levels of other forms of psychological distress, 8 months after their child's discharge from PICU. Rates of distress found were similar to those found in other groups of parents after PICU admission in the UK and the US. (Rees et al. (2004) found that 27% of parents scored above 35 on the IES, 8 months after admission; Balluffi et al. (2004) report that 21% of their sample met the criteria for posttraumatic stress disorder, 4 months after admission.) Furthermore, the hypothesis that PICU specific stress would be associated with level of posttraumatic symptomatology, was upheld. Scores on the PSS:PICU were significantly associated with those on the IES. However, no association was found, in this sample, between the severity of the child's medical condition and mothers' distress. It may be that in a critical care situation, the perceived risk to the child is so high, that mothers are oblivious to objective differences in level of dependency on life support equipment.

In interpreting these results, a number of limitations need to be acknowledged. (1) The small sample size limits the statistical power of the study. (2) The low response rate reduces the generalisability of the findings. It may have been possible to increase the recruitment rate by contacting families again by post and/or telephone, but the investigators had no option but to adhere to the stipulation of the ethics committee that families should only be contacted once, by letter. Although it is possible that this study may have been subject to response bias, it is noteworthy that two recent studies of PICU parents (see above), which had better response rates, reported similar rates of psychological distress. Also, it is also possible that the rates of distress found were an underestimate of true rates for this population, as some researchers in the field of traumatic stress have found that non-responders tend to be more distressed (and specifically more avoidant) than responders (Weisaeth, 1989). (3) The fact that stress during admission was reported retrospectively, means that it is not possible to exclude the chance that mothers' recall for events was influenced by their psychological state

at the time of interview. However, the finding in a larger group of parents ( $n=161$ ), studied prospectively, that stress at the time of admission was significantly associated with distress at follow up 4 months later (Balluffi et al., 2004), lends support to the validity of the finding that stress associated directly with events occurring during the admission is linked to subsequent distress. (4) No information was available on mothers' previous mental health or their exposure to traumatic life events between PICU discharge and interview. (5) Data on fathers are not reported here, as only half of the fathers agreed to participate, despite the fact that the interviewer was male and prepared to visit families at evenings and weekends in order not to interrupt parents' work commitments.

## Future research

Future prospective studies, on larger samples, would establish whether the association between stress at the time of admission and distress at follow up, is confirmed in this population. The lack of relationship between condition severity and mothers' distress, bears further investigation. It could be that as Balluffi et al. (2004) found, the parent's perception of risk to the child may be an important determinant of subsequent distress. In addition, it may be the case that parents are traumatised by other events they witness on the unit (e.g. resuscitation or death of other children; distress of other families). This latter hypothesis could usefully be investigated qualitatively.

The findings (a) that there was a desire for follow up and (b) that mothers who talked about their experiences were less likely to be displaying post-traumatic stress symptoms, suggest there would be value in further research into the development and evaluation of follow up services. Even if this sample is unrepresentative of the whole population of PICU parents, at the most conservative estimate, this study demonstrates that at least one in four, and perhaps up to three out of four, would appreciate a follow up appointment. The fact that those who reported having been more distressed at the time of admission, indicated that they would be more likely to attend follow up, should be borne in mind when evaluating such interventions.

Lastly, there is growing interest in the trauma literature in the measurement of the acute stress response, as it seems to be predictive of later PTSD (Freedman et al., 1999). If the retrospective associations found in this study, between particular aspects of mothers' experience on PICU and subsequent distress, are borne out by prospective studies, there are important implications for identifying

parents in greatest need of support by using appropriate screening measures.

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