

Follow-up after paediatric intensive care treatment: parental posttraumatic stress

Madelon B Bronner (m.b.bronner@amc.uva.nl)¹, Hennie Knoester², Albert P Bos², Bob F Last^{1,3}, Martha A Grootenhuis¹

1.Psychosocial Department, Emma Children's Hospital AMC, Amsterdam, the Netherlands

2.Paediatric Intensive Care Unit, Emma Children's Hospital AMC, Amsterdam, the Netherlands

3.Department of Developmental Psychology, Vrije Universiteit, Amsterdam, the Netherlands

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Correspondence

Madelon Brigitte Bronner, Emma Children's Hospital, Psychosocial Department, G8-224, Meibergdreef 9, 1105 AZ, Amsterdam, the Netherlands.
Tel.: +31(0)20-5668225 |
Fax: +31(0)20-6091242 |
Email: m.b.bronner@amc.uva.nl

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Abstract

Aim: To study the prevalence of posttraumatic stress in parents after an acute admission to a paediatric intensive care unit (PICU) and to determine risk factors for the development of posttraumatic stress.

Methods: Parents completed posttraumatic stress questionnaires three months after their child's discharge. This questionnaire measures both symptoms of posttraumatic stress disorder (PTSD) and enables determination of the full psychiatric diagnosis of PTSD. Medical and demographic data concerning their child were gathered from physical evaluations three months after discharge. Of 250 eligible families, 144 (57.6%) participated in this study. The questionnaires were completed by 140 mothers and 107 fathers.

Results: More than three-quarters of the parents experienced persistent symptoms of PTSD. In 21 mothers (15.0%) and 10 fathers (9.3%), the full psychiatric diagnosis of PTSD was determined. In six families, both parents had PTSD. Furthermore, a significant positive correlation was found between symptoms of PTSD of the mothers and the fathers. No obvious medical risk factors could be distinguished.

Conclusion: The unexpected admission of a child to a PICU is a stressful event associated with parental posttraumatic stress. Treatment should not end after discharge. Follow-up care is warranted and research should be focused on prevention of these symptoms.

INTRODUCTION

The admission of a child to a paediatric intensive care unit (PICU) is a major stressful event for parents. Parents are faced with worry about the medical treatment and the threat of losing a child. Little is known about the long-term psychological consequences for parents subsequent to their child suffering a critical illness. A posttraumatic stress model is helpful in understanding these psychological consequences. Posttraumatic stress acknowledges the direct threat to life and provides a framework for conceptualizing and treating ongoing stress (1). Parents may either develop symptoms of posttraumatic stress disorder (PTSD) or the full psychiatric diagnosis of PTSD (2–6).

PTSD is an anxiety disorder that develops after one or more stressful events (7). It includes symptoms from three clusters: intrusions, avoidance and hyperarousal. Historically, PTSD has been related to war veterans and survivors of severe disasters. Only recently has PTSD been acknowledged as an important patient-reported outcome following injury and illness (8). PTSD can persist for months or even years, resulting in serious impairment in occupational, social and relational areas when not properly diagnosed and treated (9,10).

Research on PTSD in parents after a child's admission to a PICU is scarce (2–6). Studies have identified PTSD in

approximately 18–48% of the parents. In these studies, the observed relationships between risk factors and the development of PTSD were inconsistent. Greater insight into the occurrence, risk factors and consequences of PTSD in parents is needed. The aims of the present study are (1) to examine the prevalence of symptoms of PTSD and PTSD in parents three months after discharge, following an unexpected admission of their child to a PICU, and (2) to explore the association of PTSD with potential demographic and medical risk factors.

MATERIALS AND METHODS

The project and patients

This is a prospective follow-up study at 3 and 9 months after an unexpected PICU admission, focusing on physical and psychological consequences in children and their parents. In this study we included previously healthy children, unexpectedly referred to the PICU with an acute life-threatening illness; we excluded children with known underlying illnesses or patients with scheduled elective surgery. In an attempt to include seriously ill patients only, we defined our inclusion criteria as follows: admission for respiratory insufficiency necessitating ventilatory support for at least 24 h and/or patients admitted to the PICU for at least 7 days. Furthermore, we included patients who were

admitted for trauma, respiratory syncytial virus (RSV) infection and meningococcal disease, irrespective of length of stay or necessity of ventilatory support. We suspected these patients to be at risk for long-term physical and psychological problems (3,5,8). Exclusion criteria were admission due to abuse or self-intoxication and the inability to complete Dutch questionnaires because of a language barrier. The study was conducted from December 2002 to October 2005.

The term 'previously healthy' is defined as having no need of medical supervision at any time before PICU admission. Unexpected admission is defined as an unplanned PICU admission due to a life-threatening illness. This includes children presenting at the emergency room and directly admitted to the PICU, as well as children first admitted to the general ward, whose condition then deteriorated and who were admitted in the second instance.

Procedure

After discharge from the PICU, each family received a letter at home explaining the aim and content of the research program. Families were contacted by telephone to invite participation in the research program. For cases in which no telephone contact could be made after repeated attempts follow-up letters were sent, with a tear-off reply slip inviting participation. Families who declined to participate were asked about their reasons for refusal. Participation in the research program included a visit to the follow-up clinic at 3 months and a completion of questionnaires at 9 months. The visit to the follow-up clinic at 3 months consisted of a structured medical examination of the child by a paediatric intensivist followed by a psychological screening by a psychologist. Parents filled out a validated PTSD questionnaire during this screening. Some parents only completed the questionnaires at home and did not visit the follow-up clinic (e.g. for geographical reasons). Written informed consent was obtained from all participating families. The Medical Ethics Committee of the Academic Medical Centre in Amsterdam has approved the study protocol. This article describes the data of the visit to the follow-up clinic at 3 months.

Measures

Posttraumatic stress in parents was measured with the Self-Rating Scale for Post-Traumatic Stress Disorder (SRS-PTSD) (11,12). This is a Dutch self-report questionnaire, and contains 17 items corresponding to the diagnostic DSM-IV symptoms of PTSD, divided into three clusters: intrusions (five items), avoidance (seven items) and hyperarousal (five items). With use of this questionnaire, the diagnosis of PTSD, the presence of symptoms of PTSD and a total symptom score were calculated. The diagnosis of PTSD is likely if at least one intrusion, three avoidance and two hyperarousal symptoms were present in the previous four weeks (7,12). Symptoms of PTSD were present if one of the clusters was completely present (one intrusion symptom or three avoidance symptoms or two hyperarousal symptoms). Furthermore, a total symptom score was calculated by counting all

symptoms. This continuous scale ranges from 0 (no symptoms at all) to 17 (all symptoms present).

In a study that examined the clinical utility of this questionnaire as compared with a structured interview for PTSD, the SRS-PTSD demonstrated adequate psychometric properties. In general, the clinical utility (or validity) was satisfactory, with a sensitivity of 86% and a specificity of 80%. For the 17 separate items on SRS-PTSD, $\alpha = 0.96$, which was acceptable. None of the items had to be deleted to improve α . Internal consistency for the symptom clusters was as follows: intrusion $\alpha = 0.88$, avoidance $\alpha = 0.88$ and hyperarousal $\alpha = 0.93$. The instrument was regarded as a good alternative to the structured interview for PTSD, particularly at sites that have limited clinical resources (12). In the current study, α scores were moderate to satisfactory on the three clusters and PTSD (0.76, 0.60, 0.73 and 0.87 for mothers, and 0.77, 0.52, 0.68 and 0.84 for fathers).

Clinicopathological data were obtained from medical records and the Patient Data Management System (PDMS). These data included the following: gender and age of the child, length of stay in PICU, length of ventilatory support, risk of mortality, reason for admission, and treatment characteristics. The risk of mortality was measured with the Paediatric Index of Mortality (PIM2). This is a rating index developed to predict mortality risk in the PICU. The mortality risk is calculated during the first 24 h of admission, in accordance with PIM2 guidelines (13). The reason for admission was categorized by a paediatric intensivist in respiratory insufficiency or circulatory insufficiency. These categories are not exclusive, but are based on the most significant reason for admission. Trauma was included as a distinct category.

At the follow-up clinic, the paediatric intensivist evaluated and categorized physical complications and sequelae by taking structured histories and performing a physical examination. Physical sequelae were categorized into two groups: (a) sequelae due to as yet undiagnosed, underlying illnesses (pre-PICU morbidity, PPM; e.g. a patient admitted because of cyanosis and diagnosed with an up-to-then unrecognized congenital heart defect), and (b) sequelae resulting from PICU treatment (acquired PICU morbidity, APM; e.g. a trauma patient with permanent neurological damage or a patient with meningococcal infection, suffering from postthrombotic syndrome following central venous catheterization).

Data analysis

The Statistical Package for Social Sciences (SPSS, Inc., Chicago, IL, USA), Windows version 11.5, was used for all analyses. First, missing data were imputed according to the guidelines of the questionnaire. Data were imputed if parents completed at least 90% of the questionnaire by mean scores of the other items, which was done in 6 out of 247 questionnaires. Second, internal consistency (α) was calculated for the three clusters and PTSD score. Third, non-response analyses of families were performed with regard to patient and treatment characteristics. Final analyses examined the prevalence of the diagnosis of PTSD, the presence

of symptoms of PTSD and a total symptom score in parents, using frequency tables. A Spearman rank correlation analysis examined the relation between the total symptom score of PTSD in mothers and fathers. Differences between these scores in mothers and fathers were tested by a Wilcoxon rank sum test. Finally, univariate logistic regression analyses were performed in order to assess the association between the risk factors and PTSD (dependent variable). Univariate analysis was used because of the relatively small numbers of parents with PTSD and lack of normal distribution in most variables. The risk factors analyzed were as follows: demographic characteristics (gender and age of the child), medical characteristics (length of stay in PICU, length of ventilatory support, PIM2, reason for PICU admission, treatment characteristics and physical sequelae [PPM and APM]). Moreover, all analyses were carried out separately for mothers and fathers, because dependency exists between their data.

RESULTS

Participants

Between December 2002 and October 2005, 250 families were eligible for participation in the present study. Of these families, 144 (57.6%) participated in the final study sample. No significant differences were found between those families who participated (144) and those who did not (106) regarding either patient or treatment characteristics (Table S1 in Supplementary Material online). Of the 144 families, 103 were seen by a psychologist at the outpatient follow-up clinic. Not all parents completed the questionnaire at this clinic, due to several reasons (e.g. a parent visited the clinic alone). The questionnaire was completed at the clinic by 100 mothers and 70 fathers. Of the 41 families that did not visit the follow-up clinic, an additional 40 mothers and 37 fathers completed the questionnaire at home. No significant differences were found between those families who completed the questionnaire at the clinic or at home regarding either patient or treatment characteristics. In total, results were available for 140 mothers and 107 fathers at 3 months after discharge (mean = 101 days, range 58–210).

Nonparticipants

Of the 106 families who did not participate in this study, 24 refused to participate. The most common reasons given for refusal included the following: 'everything is going well', 'we have seen too many hospitals', 'we need some rest' and 'we don't want to remember that time'. Fifty-six families said that they would like to participate but never returned their questionnaires or did not complete the full questionnaire; 23 families did not respond at all, and the addresses of three families were unknown.

Medical and demographic characteristics

Two-thirds of the children (59 girls and 85 boys) were less than 1 year old. Three-quarters of the children stayed for less than 10 days in the PICU and 90% stayed for less than 20 days. Three-quarters of the children had a less than 8% risk of mortality, and for 90% this risk was less than 16%.

In this study, 85 (59.0%) of the 144 children were admitted to the PICU with respiratory insufficiency, 32 (22.2%) with circulatory insufficiency and 27 (18.8%) had a trauma; 122 (84.7%) children needed ventilatory support, 38 (26.4%) needed circulatory support and 33 (22.9%) were treated with neuromuscular blocking agents (Table S1 in Supplementary Material online).

Physical sequelae

Ninety-nine children of the 144 families were evaluated by a paediatric intensivist at the outpatient follow-up clinic, and 21 of the remaining 45 children were evaluated by another medical specialist in our centre. Medical follow-up data were unavailable for 24 of the 144 children. Seventy-one of the 120 children evaluated (59.2%) had physical sequelae three months after discharge. Twenty-four children appeared to have PPM, 39 children had APM and 8 children had a combination of PPM and APM, resulting in 32 children with PPM and 47 with APM (Table S1 in Supplementary Material online).

Parental posttraumatic stress

PTSD could be diagnosed in 21 mothers (15.0%) and 10 fathers (9.3%) (Table 1). In total, 31 out of 247 parents (12.6%) had PTSD. On the three symptom clusters, parents scored as follows: at least one of the intrusive recollections in the 4 weeks immediately preceding the follow-up visit to the outpatient clinic were reported by 118 mothers (84.3%) and 78 fathers (72.9%). Twenty-two mothers (15.7%) and 13 fathers (12.1%) scored positively on three or more avoidance symptoms. Fifty-seven of the mothers (40.7%) and 24 of the fathers (22.2%) had two or more symptoms of hyperarousal (Table 1). Furthermore, total symptom scores of PTSD (0–17) were calculated for mothers and fathers. Mothers had a median score of 4 symptoms (range 0–16) and fathers of 2 symptoms (range 0–12). There were 104 couples who filled out the questionnaires. In six families, PTSD was diagnosed in both parents. There was a significant positive correlation between the symptoms of PTSD of the mothers and the fathers ($\rho = 0.646$, $n = 104$, $p < 0.01$). However, mothers had significantly more symptoms of PTSD than did the fathers ($z = -2.398$, n -ties = 88, $p = 0.016$).

Table 1 Parental posttraumatic stress scores on the three clusters (intrusions, avoidance and hyperarousal) and PTSD, three months after paediatric intensive care treatment of their child

	Mothers (n = 140)		Fathers (n = 107)	
	n	%	n	%
Intrusions (≥ 1 symptom)	118	84.3	78	72.9
Avoidance (≥ 3 symptoms)	22	15.7	13	12.1
Hyperarousal (≥ 2 symptoms)	57	40.7	24	22.4
PTSD*	21	15.0	10	9.3

*A diagnosis of PTSD is indicated if at least one intrusion, three avoidance and two hyperarousal symptoms have been present in the previous four weeks.

Table 2 Odds ratios and 95% CI of risk factors for PTSD in mothers and fathers

	Mothers (n = 140) n = 21 with PTSD		Fathers (n = 107) n = 10 with PTSD	
	OR	95% CI	OR	95% CI
Age of child (years)	1.07	0.99–1.16	0.99	0.86–1.14
Length of stay in PICU (days)	0.99	0.97–1.02	1.01	0.99–1.02
Length of artificial ventilation (days)	1.00	0.96–1.04	1.04	0.99–1.09
Risk of mortality, PIM2 (%)	0.98	0.92–1.05	1.01	0.95–1.08
Gender of child (female/male)	1.08	0.42–2.74	0.64	0.16–2.62
Main reason for PICU admission				
Respiratory insufficiency (reference)	1		1	
Circulatory insufficiency	0.39	0.08–1.82	0.32	0.04–2.80
Trauma	1.54	0.52–4.55	1.80	0.40–8.06
Artificial ventilation (yes/no)	0.59	0.13–2.76	1.96	0.37–10.40
Circulatory support (yes/no)	1.18	0.40–3.48	4.23	0.51–34.85
Neuromuscular blocking agents (yes/no)	0.94	0.32–2.80	0.77	0.18–3.20
PPM (yes/no)	3.25	0.70–15.06	1.21	0.23–6.33
APM (yes/no)	0.28	0.10–0.8*	0.46	0.11–1.86

PPM = sequelae due to underlying disease, n = 115 for mothers and n = 83 for fathers.

APM = sequelae due to PICU treatment, n = 115 for mothers and n = 83 for fathers.

*Significant at $p < 0.05$.

Medical and demographic risk factors for PTSD

Logistic regression gave no significant odds ratios for demographic and medical characteristics in mothers and fathers. Only for APM in mothers did there emerge a significant odds ratio ($B = -1.265$, $OR = 0.28$, $95\% CI 0.10-0.82$, $p = 0.02$) Mothers of children with APM had significantly more PTSD than did mothers of children without APM (Table 2).

DISCUSSION

In this cohort of parents of previously healthy children admitted to the PICU, we found evidence of distinct symptoms of PTSD. Moreover, one in eight of the parents fulfilled the criteria for a full diagnosis of PTSD three months after discharge. Furthermore six couples had PTSD, and a positive correlation was found between the symptoms of PTSD in mothers and fathers. In addition, no obvious medical risk factors for the development of full diagnosis of PTSD could be distinguished.

This study confirms earlier follow-up outcomes regarding PTSD in parents after PICU admission, in which 18–48% of parents develop PTSD (2–5). Previous research has also documented PTSD in parents following a variety of other stressful medical events, including accidents, cardiac surgery and childhood cancer (14–18). In these populations, the prevalence of PTSD among parents differs according to the type of stressful event. This difference can also be attributed to the use of diverse measures for PTSD. For example, studies use different cutoff points for PTSD (19). Follow-up research in the medical setting after injury or illness should ideally incorporate a uniform approach, with standardized measures of posttraumatic stress outcomes. In addition, a continuum of symptoms of PTSD may be more broadly applicable to parents than the dichotomous psychiatric diagnosis of PTSD.

Moreover, symptoms of PTSD can cause impairment similar to the full diagnosis of PTSD (20). Even in light of the limitations described above, the overall picture that emerges from these studies shows that symptoms of PTSD in parents are a common consequence of stressful medical events, including PICU treatment. Paediatricians should be aware of the impact on parents of a child's critical illness, especially as children are dependent on their parents.

One strength of this study was the large number of fathers included. Until now, research has focused mainly on stress experienced by mothers with a child in the PICU, but there is a lack of research on the experiences of fathers with critically ill children. If researchers are to understand the impact of a paediatric intensive care treatment on families, then both mothers and fathers must be included. Moreover, it is interesting to note that in six families both parents had PTSD, and a strong correlation was found between symptoms of PTSD of the parents. Although mothers score significantly higher than fathers, these findings suggest an association between posttraumatic stress reactions in mothers and fathers. A number of explanations are possible for the distribution of these stress reactions within families. For example, characteristics common to mothers and fathers (e.g. lack of social support during hospital admission) may contribute to the development of symptoms of PTSD (21). Another interpretation for this finding is the theory of secondary traumatic stress (i.e. the fact of being in close contact with and emotionally connected to a traumatized person becomes a chronic stressor) (22).

This study also attempted to identify risk factors for the development of parental PTSD after paediatric intensive care treatment. Because the majority of the parents in our study and other studies are resilient and recover without any significant stress symptoms, it is important to identify parents who are at risk. Once these parents are identified,

psychological support can be offered at an early stage, aimed at minimizing symptoms of PTSD. The only relationship that we found was between the development of PTSD in mothers and the physical sequelae of PICU treatment (APM). Stress theories have described three properties of events that make them more or less stressful: novelty, predictability and uncertainty (23). Thus far, little is known about the long-term effects of physical sequelae subsequent to PICU treatment. This possibly causes more uncertainty about future health outcome than do known chronic illnesses (PPM). Uncertainty and the absence or loss of control lead to more stress symptoms (23,24). We did not find relationships between the development of PTSD and risk of mortality or length of stay in the PICU, which have been found in previous studies. Earlier results have shown that parents whose children were more seriously ill and were admitted for a longer period had a greater risk of developing PTSD (3–5). These studies, however, were based on small numbers of parents, included children with a homogeneous medical diagnosis (e.g. meningococcal disease) and included mothers in particular. In a larger sample of parents, parental PTSD did not correlate with objective medical severity of illness, but was related to the subjective perceptions of the threat to their child's life (2). We did not analyze personal characteristics, such as history of prior trauma or history of psychopathology, that can also contribute to the development of PTSD (25,26).

There are several clinical implications that can be drawn from this study, both for the acute and the follow-up phases. Psychological consequences may be minimized by anticipatory guidance and stress reduction interventions during and after PICU treatment (27,28). For example, a protocol to inform and prepare parents for transfers out of the PICU could offer a foundation for security and safety and reduce distress (29). Outpatient follow-up clinics should evaluate psychological consequences in a structured way and refer parents to appropriate healthcare providers if necessary (30). Because reason for admission, length of stay and length of artificial ventilation were not risk factors for parental PTSD, we now invite all previously healthy children who were unexpectedly admitted to our PICU to visit the follow-up clinic.

A number of limitations to this study should be taken into account. First, a considerable number of families were lost due to nonresponse and refusal. Although other follow-up studies in the PICU have had similar response rates, this could have biased our results (2–6). We probably failed to see a number of parents who were experiencing psychological problems, as avoidance and refusal to come back to the hospital are symptoms of PTSD. Furthermore, we included a predominantly white European population. The results of this study are not necessarily to be extrapolated to parents from other ethnic or cultural communities. In addition, a structured clinical interview can be regarded as the best measurement for PTSD. The use of digital self-reports only gives an indication for the diagnosis of PTSD. Self-reports can give overestimations of the rate of PTSD. Recent findings suggest that people screened positive for PTSD may actually

not have the disorder (31). However, the sensitivity of the SRS-PTSD, which is used in this study is satisfactory (86%). This means 86% of the respondents with a PTSD diagnosis on SRS-PTSD had received the right diagnosis (12). Finally, only a limited number of determinants (i.e. medical characteristics, demographic characteristics and physical sequelae) could be investigated in this study. Other personal characteristics (e.g. parents' assessment of the severity of the illness, history of psychopathology, recent life events or even neuro-endocrine changes) are likely to play a more prominent role in the development of PTSD (9,10,25,26). Family dynamics can also play a role in the development of PTSD. Future research should examine the mechanisms between parents, family dynamics and other probable risk and protective factors, in order to gain more insight into the parents who are most at risk of developing PTSD (32).

CONCLUSIONS

The unexpected admission of a previously healthy child to a PICU is a stressful event that is associated with symptoms of PTSD and PTSD in parents. Paediatricians who are involved in the care of PICU children should be aware of the impact that such an event may have. One in 8 of the parents met criteria for PTSD three months after intensive care treatment. The prevention of PTSD through early detection and intervention is of importance in reducing the harmful effects that a child's critical illness can have on the well-being of parents. Parents should therefore be monitored carefully in order to provide additional support—including information, emotional and educational guidance in coping with the stressful event of critical illness and PICU treatment. Treatment should not end after discharge. Follow-up care is warranted, and research should be focused on the prevention and reduction of these symptoms.

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Supplementary material

The following supplementary material is available for this article:

Table S1 Demographic and medical characteristics and physical sequelae.

This material is available as part of the online article from: <http://www.blackwell-synergy.com/doi/abs/10.1111/j.1651-2227.2007.00600.x>

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