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Pediatric medical traumatic stress (PMTS) in parents of newborns with a congenital anomaly requiring surgery at birth

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ABSTRACT

Background: Pediatric medical traumatic stress (PMTS) is a psychological and physiological response of children and their families to pain, serious illness, and invasive medical procedures. We aimed to apply the PMTS model to parents of newborns operated at birth for a congenital malformation and to identify clinical and sociodemographic risk factors associated with PMTS symptoms at 6 months.
Methods: We designed a cross-sectional study to assess PMTS symptoms (avoidance, arousal, reexperiencing) in parents of six months children operated on for a congenital anomaly, with the Italian version of the Impact of Event Scale – Revised (IES-R).
Results: One-hundred-seventy parents form the object of the study. Eighty-two parents (48.2%) fell over the clinical cut-off. Ventilatory time ($p = 0.0001$), length of hospital stay ($p = 0.0001$), associated anomalies ($p = 0.0002$), medical devices at discharge ($p = 0.0001$) and Bayley motor scale ($p = 0.0002$) were significantly correlated with IES-R Total and Subscale Scores.
Multivariate linear regression showed length of hospital stay and number of associated anomalies as significant predictors of IES-R Scores.
Conclusions: Regardless the type of anomaly and sociodemographic factors, it is the clinical history of the child which seems to predict the severity of PMTS symptoms in this population of parents. PMTS represents a useful model to describe the psychological reactions of parents of newborns operated at birth for a congenital malformation. NICU and outpatient pediatric staff should be aware of risk factors to identify families who may request early multidisciplinary interventions since the first admission.
Level of evidence: Prognosis study, level II.

Parents of children experiencing life-threatening conditions, such as cancer, burns, traffic injuries, prematurity and cardiac surgery often present posttraumatic stress symptoms (PTSS) [1–6]. Literature indicates that the incidence of PTSS in mothers of children hospitalized in the NICU ranges from 5% to 64% and from 8% to 40% in fathers [7]. Different authors have investigated the experience of giving birth to a child with a congenital anomaly requiring surgery and its traumatic aspects, finding high percentages of PTSS [8–12]. This is an important field of research since PTSS in parents can lead to disruptions in parenting, namely more controlling and less sensitive interactions, impaired cognition, behavior problems, and inappropriate use of health care [13–16]. More recently, the National Child Traumatic Stress Network defined psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experience as pediatric medical traumatic stress (PMTS) [17]. PMTS is not a traumatic stress disorder but a set of symptoms, including arousal, reexperiencing, and avoidance that might be present without meeting clinical criteria for PTSD diagnosis [17]. The PMTS model is developmental and recognizes that the trauma unfolds over the course of an illness and treatment, including across the period of an infant's hospitalization in a NICU [18]. This Integrative Model describes child and family adjustment across three consecutive phases: Phase I — peritrauma, includes the initial potentially traumatic event (PTE) and surrounding events; Phase II — early, ongoing, and evolving responses, includes active medical treatment and related demands; Phase III — longer-term PMTS, refers to the time past the end of active medical treatment, highlighting the potential for traumatic responses to continue for months or years [19].

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We aimed to apply PMTS model to parents of newborns operated at birth for a congenital malformation and to identify clinical and sociodemographic risk factors associated with posttraumatic stress symptoms (PTSS) at 6 months (Phase III).

1. Material and methods

A cross-sectional study was designed with parents of children born with a congenital anomaly from January 2015 to December 2016. In order to apply the PMTS model, we assessed PTSS at six months of age (Phase III of the model), and we analyzed potential associated risk factors. The setting was that of multidisciplinary standardized follow-up care, which is offered to all infants seen at our institution with major anomalies requiring surgery in the neonatal period. Infants are submitted to a comprehensive evaluation by pediatrician, surgeon, and psychologist at preset time frames. Children were affected by thoracic or/and abdominal anomalies, while those with urological, brain, and cardiac anomalies were excluded since they were cared for by other services. To avoid confounders, parents were excluded from the study if one of the following criteria was present in their child: 1) genetic or chromosomal anomaly; 2) cerebral palsy; 3) language barriers; 4) <33 weeks prematurity.

Upon discharge, parents of surgical patients were asked by the psychologist to participate in the ongoing study. Those who agreed to participate were enrolled. Written parents' informed consent was obtained. The study was IRB approved.

Clinical data of the child and sociodemographic data of the parents were collected during hospitalization. The *Bayley Scales of Infant and Toddler Development – 3rd Edition (BSID-III)* [20] was used to evaluated infants at both 6 and 12 months. The BSID-III is an internationally recognized, clinician-administered tool designed to assess the development of very young children (1–42 months). It consists of three scales, of which we used cognitive and motor ones. This standardized test for infant development is age normed to have a mean of 100 and a standard deviation of 15. Infants with a standard score between 85 and 70 were considered moderately delayed; those with a standard score < 70 were considered very delayed.

Socioeconomic status was classified according to European Socio-Economic Classification into: salariat, intermediate, working class, or unemployed [21]. Reasons of unemployment were not investigated.

To assess PTSS, we used the Italian version of the Impact of Event Scale – Revised (IES-R), which is one of the key assessment methods in traumatic stress research [22–24]. The IES-R is a 22-item self-report measure assessing subjective distress caused by traumatic events. Items are rated on a 5-point scale ranging from 0 ("not at all") to 4 ("extremely"). The IES-R yields a total score (ranging from 0 to 88) and has a cut-off point of 24 for determining clinically significant trauma. Scores can also be calculated for the three Subscales investigating the three main PMTS symptoms (Re-Experiencing, Avoidance, and Arousal) [25] ; mean item score > 1.5 indicating clinical concern. Re-Experiencing (total score range 0–28) deals with unbidden thoughts and images, troubled dreams, strong waves of feelings, and repetitive behavior related to the baby's congenital malformation; Avoidance (total score range 0–32) deals with denial of the meaning and consequences of the baby's congenital malformation, blunted sensation, behavioral inhibition, and awareness of emotional numbness; Arousal (total score range 0–28) deals with reduced hours of sleep, difficulty in concentrating, hypervigilance or feeling on edge in a number of situations and exaggerated startle responses. Associations between children's clinical characteristics, neurodevelopmental outcome at follow-up, and parental socioeconomic status with IES-R parental scores were analyzed.

Correlations were computed between IES-R total score, IES-R subscales scores, and the following clinical and sociodemographic variables: prenatal diagnosis, gestational age, weight at birth, type of anomaly, number of surgical intervention, ventilatory time, duration hospital stay, medical device at discharge, brothers parenting order, cognitive and motor development, distance from home, parental age, parental educational level, mothers vs fathers, socioeconomic status, nationality.

Four multiple regression models were performed to investigate risk factors related to IES-R total score and IES-R subscales scores. The independent variables were chosen for inclusion in the final models if significantly related at $p < .001$ to IES-R total and subscales scores in bivariate relations. Bootstrapped confidence intervals (95%) were computed.

Data were analyzed using GraphPad Prism 5.0 Macintosh Version (GraphPad Software, San Diego, CA, USA; www.graphpad.com). For continuous variables, the correlation was analyzed using Pearson's test. For dichotomous variables we used unpaired t-test. To compare variables with more than two samples (mostly socioeconomic variables) we used one-way ANOVA. Results are reported as mean +/ −standard error, except where otherwise specified. Because IES-R score was tested against several hypothesized risk factors, a Sydak-adjusted significance level of 0.003 was calculated to account for the increased possibility of type-I error. Two-sided p values are reported.

2. Results

Over the study period, 184 children entered the follow-up program. Of these, 40 were not included in the study according to exclusion criteria (14 language barrier, 5 syndromes, 1 stroke, 20 preterms <33 weeks of gestational age). One hundred seventy parents (94 mothers and 76 fathers) of 95 children (66%) filled the IES-R at 6 months after birth. Clinical data of children and socioeconomic status of parents are reported in Tables 1 and 2, respectively. At 6 months, mean (sd) IES-R total score was 26.4 (16.0); 82 parents (48.2%) fell over the clinical cut-off. As to subscales' scores, mean item scores were: 0.97 for Avoidance; 1.51 for Re-Experiencing; 1.15 for Arousal. Significant correlations of IES-R Total and IES-R subscales scores with clinical and sociodemographic variables are reported in Table 3**.** Gestational age, weight at birth, type of diagnosis, number of surgical intervention, prenatal diagnosis, brothers parenting order, cognitive development, distance from home, parental age, parental educational level, mothers vs. fathers, socioeconomic status, and nationality did

Table 1
Clinical data of children.

Variables	$n = 95$	
Male, *n* (%)	50	(52.63)
Gestational age, median (IQR)	38	(36–39)
Weight at birth, median (IQR)	2860	(2400–3147.5)
Prenatal diagnosis, *n* (%)	48	(50.53)
Type of anomaly, *n* (%)		
CDH	17	(17.89)
AE	20	(21.05)
AWD	7	(7.37)
MM	28	(29.47)
CM	16	(16.84)
Others	7	(7.37)
Associated malformation		
0, *n* (%)	87	(91.58)
1, *n* (%)	5	(5.26)
>1, *n* (%)	3	(3.16)
Ventilator time days, median (IQR)	4	(0–5)
Number of surgeries, median (IQR)	1	(1–2)
Length of hospital stay days, median (IQR)	35	(21.5–65.5)
Brothers parenting order		
First, *n* (%)	57	(60.00)
Second or more, *n* (%)	38	(40.00)
Number of medical devices, *n* (%)		
None	69	(72.63)
1	21	(22.11)
2 or more	5	(5.26)
Bayley III Motor scale, mean (SD)	97.94	(18.33)
Bayley III Cognitive Scale, mean (SD)	89.01	(16.09)

IQR, interquartile range.

Table 2
Sociodemographic variables of parents.

Variables	$n = 170$	
Mothers, *n* (%)	94	(55.29)
Fathers, *n* (%)	76	(44.71)
Age mothers, median (IQR)	35	(30.75–38)
Age fathers, median (IQR)	37	(33–42)
Educational level, *n* (%)		
Primary	0	(0)
Secondary school	17	(10.00)
High school	91	(53.53)
Graduation	62	(36.47)
Socioeconomic status, *n* (%)		
Salariat	27	(15.88)
Intermediate	83	(48.82)
Working class	36	(21.18)
Unemployed	24	(14.12)
More than 200 km from home, *n* (%)		
Rome	91	(53.53)
Outside the region	79	(46.47)
Nationality, *n* (%)		
Italian	165	(97.05)
Foreign	5	(2.95)

IQR, interquartile range.

Table 3
Significant associations between IES-R total score, IES-R subscales scores and clinical variables.

Variables	IES-R Tot	IES-R Hyperarousal	IES-R Intrusion	IES-R Avoidance
Ventilatory time	.392*	.396*	.337*	.314*
Length of hospitalization	.461*	.506*	.394*	.318*
Associated anomalies	11.061**	11.355**	8.886**	6.005**
Medical devices at discharge	11.420**	13.054**	8.252**	6.404**
Bayley Motor Index	−.296*	−.292*	−.286*	−.198*

* Pearson's test ($p < 0.0002$).
** One-way ANOVA ($p < 0.003$).

not result to be significantly associated with IES-R total and subscales scores.

Results from the significant multivariate linear regression models are reported in Table 4. Main findings showed length of hospital stays as a significant predictor of IES-R total [$F(5, 156) = 11.745$, $p = .000$; $R^2 = .28$], IES-R Hyperarousal [$F(5, 157) = 14.086$, $p = .000$; $R^2 = .32$] and IES-R Intrusion scores [$F(5, 157) = 8.115$, $p = .000$; $R^2 = .21$]. Moreover, number of associated anomalies resulted related to IES-R total scores and IES-R Intrusion subscale scores. None of the studied variables significantly predicted IES-R Avoidance subscale scores [$F(5, 157) = 5.499$, $p = .000$; $R^2 = .15$].

3. Discussion

Multiple studies have shown that the birth of a baby with a congenital anomaly and the baby's subsequent hospitalization in a neonatal intensive care unit (NICU) are significant sources of parental distress [26–33]. Moreover, the course of the illness and treatment, as well as infants' physical vulnerability and the uncertainty of prognosis, often produces additional psychological distress in their parents [18,29,34–36].

To date, limited attention has been paid to the relationship between the medical history of the child and the development of parental PMTS symptoms in the postnatal period in this specific population. In other words, little is known about what particular factors might be associated with PMTS among parents of newborns operated on at birth. According to the PMTS model there are 4 distinct trajectories of adjustment over time: resilient (minimal PTSS following injury), recovery (minimal initial PTSD or elevated PTSS that remain within 1–3 months), chronic (consistently elevated PTSS or PTSD for 6–24 months postinjury) and delayed onset (PTSD diagnosis 6 months postinjury) [19]. In our sample, half of the parents (51.8%) showed a resilient or recovery trajectory, while 48.2% showed a total IES-R Score above clinical cut-off, suggesting a chronic trajectory. We were unable to assess if, in our sample, there were cases of delayed onset since IES-R was administered only at 6 months from birth. This finding confirms PMTS as a useful model to bring to light the psychological pain of parents of children experiencing life-threatening congenital anomalies. Moreover, this finding underlines the need to support parents and families from NICU throughout follow-up, as the risk for increased parental distress and mental health disorders represents, in turn, a risk for the relationship they are developing with their infant [37–39]. In this regard, in our institution since prenatal diagnosis of congenital malformation couples are offered a psychological support throughout pregnancy. In the postnatal period, from admission in the NICU to dismissal, parents are offered individual and/or couple psychological sessions. Results of the present study suggested the need for a more structured approach to support parents throughout this traumatic experience and mitigate the development of PMTS. In this regard, the pediatric preventative health model proposed by Kazak et al. [40] identifies three-tiered approach to support families, which is based upon the specific family's level of need as they adjust to their child's medical condition: the levels are universal, targeted and clinical. As suggested by Hynan et al. [41], a 'universal' level of care should be available to all parents [41]. This universal care level is best addressed with family-centered developmental care along with active parent-to-parent support. A higher level of 'targeted' care should be

Table 4
Multivariate linear regressions for the total sample: risk and protective factors for IES-R Total score and IES-R subscales scores.

Outcome	Variables reached significance of $p < .001$ at bivariate correlations	B	Bootstrap 95% CI [LLW to LLU]
IES-R Tot	Ventilatory time	-	-
	Length of hospital stay	.132	.037 to .198*
	Associated anomalies	7.313	.844 to 13.214*
	Medical devices	-	-
	Bayley Motor Index	-	-
IES-R Hyperarousal	Ventilatory time	-	-
	Length of hospital stay	.064	.025 to .093*
	Associated anomalies	-	-
	Medical devices	-	-
	Bayley Motor Index	-	-
		-	-
IES-R Intrusion	Ventilatory time	-	-
	Length of hospital stay	.037	.000 to .066*
	Associated anomalies	2.828	.076 to 5.170*
	Medical devices	-	-
	Bayley Motor Index	-	-

* $p < .01$.

provided for families identified as being at risk for emotional distress. Both professional and paraprofessional levels of 'targeted care' should be delivered by NICU staff. 'Clinical' care is emotional care provided for NICU parents with acute or diagnosable conditions by mental health professionals both within the NICU and through outside referrals. We agree with Hynan et al. [42,43] that psychological service within NICU should assess at admission the psychosocial needs and resources of the family in order to meet the various levels of family need. Literature suggests a variety of treatment approaches, including interpersonal therapy, short-term dynamic therapy, cognitive therapy, behavior therapy, couples and family therapy, mindfulness training and infant mental health. Interventional studies are advocated to assess the best treatment approach for this specific population.

When considering associated risk factors for PMTS, literature is still limited and controversial. To date, most of the literature focused on PTSS in mothers of children hospitalized in the NICU finding an incidence ranging from 5% to 51%, whereas in the few studies including fathers, the incidence ranged from 8% to 33% [5,26,44,45]. In contrast to the general literature, which shows a higher vulnerability in mothers, we did not observe a significant gender difference in traumatic responses. In other words, in the time past the end of active treatment, a high percentage of both mothers and fathers presents symptoms of the PMTS. Our data are in line with Aftika and colleagues [26] who reported that the differences in the prevalence of PTSS in the mothers and fathers of infants hospitalized in the NICU (51% and 33%, respectively) were not statistically significant. This finding highlights the equally high risk for psychological maladjustment in relation to a newborn undergoing surgery, both in mothers and in fathers [5,44,46]. This finding seems to corroborate our previous study suggesting that NICU and follow-up program should be couple-centered rather than mother-centered [46].

With regard to the influence of demographic factors on the occurrence of PTSS, in the population of parents of children hospitalized in the NICU, it is still not well understood. Some authors reported statistically significant impacts of several demographic factors, while others negated it [44,47]. Our data are in line with that reported by Lefkowitz et al. [5] suggesting that parents' age, nationality, distance from home, socioeconomic status, and level of education do not seem to play a significant role in determining PMTS symptoms. In other words, according to our data, sociodemographic data should not be taken into consideration to identify subjects and families at risk.

As previously mentioned, we also considered the relationship between clinical variables and the onset of PMTS symptoms. Our data highlight several potential risk factors in this specific population: duration of hospital stay, days of mechanical ventilation, presence of associated anomalies, medical devices at discharge, and motor score at Bayley III at six months. Our data are consistent with that reported by Holditch–Davis et al. [29] with mothers of high-risk premature babies, who reported that infant illness was unrelated to maternal PTSD symptoms, and in contrast with few studies reporting that illness severity was related to maternal PTSD symptoms [15,28]. In particular, our findings with regard to the duration of ventilatory time are in line with that reported by Chang and colleagues [48] in mothers of preterm infants. These data seem to suggest that postoperative intensive care may impose further distress on parents owing to the sight of their mechanically, fragile, at-risk ventilated child. According to literature, parents' subjective interpretation of medical events such as the perception of life-threat is one of the most powerful predictors of PMTS [19]. Regarding hospital stay, our data are only partially in line with that reported by Helfricht et al. [6] in parents of children with CHD. According to this author overall duration of hospital stay correlates with the psychological state of fathers at 6 months and with the use of social service in mothers. According to the same author duration of intensive care does not significantly contribute to the prediction of maternal PTSD severity at 6 months.

Interestingly PMTS symptoms in parents were significantly inversely correlated with motor development at 6 months: higher scores on the motor scale were associated to lower scores in parental PMTS. There is a growing body of research on the detrimental effect of maternal anxiety on infant and child development [49,50]. As reported by Cook and colleagues [51] in a systematic review, evidence of an association between maternal PTSD and child development is still contradictory. Our clinical experience suggests considering motor outcome as a protective factor for parental PMTS, which seems to depend not so much upon the stressor as to how one copes with stress [52]. In other words, we can speculate that having a child achieving on-time developmental milestones could be considered a protective factor that affects parental psychological status. Nevertheless, further studies are needed in our study population to asses if PMTS symptoms affect motor delay or vice versa.

The significant correlation between medical devices at dismissal and parental PMTS symptoms at six months underlines the extra strain this may represent for families regardless of the type of anomaly, reflecting long-term challenges related to having a child with a malformation. In this regard, Ludman et al. [53] suggested that caring for a child with a medical device constantly reminds parents that their child was born with a life-threatening condition.

Further analysis was performed to identify risk factors able to predict higher level of PMTS symptoms. Interestingly, length of hospital stay and number of associated malformations were the only significant predictive variables. This result highlights the importance of the clinical history of the child in predicting PMTS, which is in contrast with Helfricht et al. [6] who underlined the relevance of interpersonal rather than surgery-specific variables. Our result could be useful to easily identify parents at risk who deserve particular attention during recovery and a closer follow-up after dismissal. It would be worthwhile to perform farther studies to confirm this result and identify specific cut-off values (days of hospital stay, number of associated malformations) predicting clinical PMTS symptoms.

This study present some limitations: we do not have PMTS symptoms assessment in Phase I and II of the model so we cannot differentiate between chronic trajectory and delayed onset; this is a single-centered study and the size of the sample, although considerable owing to the rarity of studied conditions, does not allow definite conclusions; finally, it is important to emphasize that our correlational results show only relations and not causality between variables; therefore, they should be interpreted with caution. Further studies on this topic are advocated in order to gain more information about trauma processing considering this specific population and interventional studies to assess the best treatment approach for this specific population.

4. Conclusions

The birth of a child represents a traumatic experience. PMTS represents a useful model to describe psychological reactions of parents of newborns with a life-threatening congenital anomaly requiring surgery. After the time past the end of active medical treatment, only half of parents show a resilient or recovery trajectory. Regardless of the type of anomaly and sociodemographic factors, it is the clinical history of the child which seems to predict the severity of PMTS symptoms in this population of parents. NICU and outpatient pediatric staff should be aware of risk factors in order to identify families which may request early multidisciplinary interventions since the first admission.

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The authors have no conflict of interest to declare.

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