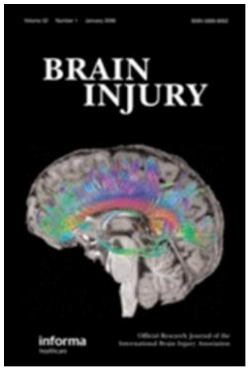

Parental Stress and Pediatric Acquired Brain Injury

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Abstract

(1) Objective

Studies on parental stress following childhood acquired brain injury (ABI-including brain tumors (BT) and other brain injuries) are scarce. The aims of this study were therefore to assess maternal stress in a sample of children and adolescents diagnosed with severe pediatric ABI.

(2) Methods

Seventy-eight X-speaking mothers of 37 children with BT and 41 with other ABIs completed the Pediatric Inventory for Parents (PIP), the State-Trait Anxiety Inventory (STAI) and the Family Assessment Device (FAD) at a mean time since diagnosis of 1.5 years.

(3) Results

The PIP correlated significantly with the STAI and the FAD. Socio-demographic factors, such as the age of mother and child, and the mother's educational level, were correlated with both maternal stress and anxiety. Maternal stress scores were comparable between groups. Emotional functioning was the most markedly affected domain, followed by parental role.

(4) Conclusions

Emotional stress as assessed by the PIP in mothers of children with ABI is considerable, and should motivate specific psychosocial interventions.

Keywords: Maternal Stress, Acquired Brain Injury, Brain Tumor, Traumatic Brain Injury, Childhood Stroke, Questionnaires, Interventions

Parental Stress and Pediatric Acquired Brain Injury

BACKGROUND

Pediatric brain injuries, and more generally pathologies of the Central Nervous System (CNS), are considered amongst the most difficult illnesses for parents[1], leading to deep concerns about future sequelae[2,3] and to high stress levels linked to uncertainty about their child's future[4]. The three most frequent types of pediatric acquired brain injury (ABI) are traumatic brain injury, brain tumors (BT), and childhood stroke. BTs are the most frequent solid pediatric tumors[5], and in France, traumatic brain injuries are the leading cause of death and acquired disability during childhood[6].

Parental stress occurring during severe pediatric illnesses is now acknowledged in the DSM-V as "acute stress" or "post-traumatic stress", on the basis of several symptoms such as intrusion and negative mood, which can lead in case of pediatric cancer to depression[7,8,9], attention disorders and other cognitive impairments[10,11]. Therefore, the educational role of parental function could be seriously affected by the stress that pediatric ABI induce. Moreover, several recent studies have shown that children's recovery after cancer is influenced by parental socioeconomic status[12,13] and education level[7,14], and the same association has been reported in traumatic brain injury[15-18].

Children with malignant BT, a cancer-induced chronic illness, have to face specific, sometimes aggressive treatments (neurosurgery, chemotherapy, irradiation) in addition to the brain lesion itself. They often suffer treatment-related sequelae, both physical and neurocognitive (including impaired health, endocrine deficits, cognitive and social skill deficits, and learning difficulties)[18-21]. Hence, once a diagnosis for BT is given, parents who at first fear their child might die, may later feel distressed about subsequent school achievement after recovery. They can also face long-term uncertainty and the burden of caregiving, even

when their child is off treatment[22]. Parental stress in pediatric cancer is generally characterized by a repetition of traumatic episodes (from diagnosis to remission), which generates increased levels of parental stress[7,8]. Because traumatic brain injuries, unlike brain tumors, are sudden, parental stress is often compared to the stress of parents whose children have other sudden traumatic orthopedic injuries[2,3]. Results have shown that parental stress is greater in case of moderate and severe traumatic brain injury, compared to orthopedic injuries[2,3], even if it declines over time[2,23].

Lastly, the pediatric stroke population is characterized by diverse functional and cognitive deficits[24.] Although studies on the role of families in pediatric stroke are scarce[25], they have shown that the family environment contributes to psychological difficulties after brain insult: family functioning is a major predictor of children's social adjustment[26] and social competence[27]. Recently, Greenham et al. (2015)[25] have shown that poorer parental mental health predicted more internalizing and social problems and lesser social participation in children with chronic illness, such as arterial ischemic stroke and asthma. However, to our knowledge, parental stress in pediatric stroke has not often been studied as well as research on stress among parents of children with BT[28].

The main aim of this study was to examine parental stress following severe ABI (BT and other types of ABI), using a X-validated version of the Pediatric Inventory for Parents (PIP)[29]. A secondary aim was to investigate whether parental stress differed according to the type of ABI (BTs versus traumatic brain injury and childhood stroke). Indeed, BT can lead to life-threatening situations and concern in the face of a lethal disease, whereas other types of ABI are more likely to lead to emotional reactions linked to the suddenness of the injury and concerns about neurocognitive sequelae.

Overall, the present study sought to characterize specific parental stressors in both types of severe ABI, in order to provide indicators and to schedule targeted interventions following diagnosis.

METHODS

Participants

Participants were selected from two hospitals near Y, specialized in the treatment of pediatric cancers and in the rehabilitation and follow-up of children with ABI. Inclusion criteria were: having been diagnosed at least one month previously with a malignant brain tumor, a severe traumatic brain injury or childhood stroke, whether or not the child was still under treatment. For the parents, the criterion was being able to understand, speak and read X. Since mothers are more frequently present than fathers during medical visits in this population, only the mothers were asked to complete the questionnaires. Of the 97 eligible mothers who were approached, 78 gave their consent and participated in the study (80% participation rate). All questionnaires were rendered anonymous in order to keep the data confidential.

Procedure

The study was approved by the ethics committees of both participating institutions. The questionnaires and the aims of the study were explained to the mothers either by their treating physician or by the researchers while they were contacted on the occasion of a medical visit. The mother's sociodemographic characteristics were collected either from their completed questionnaires or from the child's medical records. Data regarding the child's clinical information was collected by the treating clinician, or completed by the researchers from the hospital's medical records.

Measures

Socio-demographic and medical data

The mother's age, marital status and occupation were collected, as well as the child age at assessment, age at diagnosis and clinical information, such as whether the child was currently under treatment and if he or she presented any motor or cognitive sequelae.

The mother's occupation was used as a proxy for her educational level. A binary variable was generated: *high* educational level if the occupation required having a higher education diploma and *low* if not. Marital status was also dichotomized into married/living with partner *vs*. divorced/widowed or single.

For children, we generated two comparable groups according to the type of ABI: one group included children treated for BT and another composed of children with other ABI, namely traumatic brain injury and childhood stroke. Clinical information pertaining to the child was dichotomized into under treatment *vs.* not under treatment and absence *vs.* presence of motor or cognitive sequelae, which included medical complications such as epilepsy, hearing loss, visual deficits, hemiplegia, and developmental delays, among others.

Pediatric Inventory for Parents (PIP)

The PIP[29] includes 42 items grouped into four domains: communication (COM, N=9 items, e.g. "speaking with doctor"), emotional functioning (EMO, N=15 items, e.g. "learning upsetting news"), medical care (MEDI, N=8 items, e.g. "helping my child with medical procedures"), and role function (ROLE, N=10, e.g. "being unable to go to work/ job"). Mothers rated each statement on a five-point scale: from 0 (never/not at all) to 5 (very often/extremely difficult). For each statement, both the frequency of occurrence and the level of difficulty associated with the illness were rated. Total scores for the Frequency (PIP-Frequency) and the Difficulty (PIP-Difficulty) subscales were calculated by summing the responses to the total number of items of each subscale (maximum total score range=40 to 75). Higher scores express increased levels of concern about the illness. To compare the scores between the four domains, we computed adjusted means for each domain by dividing

the sum of the responses to domain-specific items for the number of items in each domain (range=1 to 5).

State Trait Anxiety Inventory (STAI)

The X version of the STAI[30] is a 40-item questionnaire assessing the respondents' present state of stress (State, 20 items) and his/her general inclination toward anxiety (Trait, 20 items). Mothers rated each statement on a four-point scale from 1 (not at all) to 4 (very much so) for the State scale, and from 1 (almost never) to 4 (almost always) for the Trait scale. A total score for each scale was obtained by summing the items in the Trait and the State scales (maximum=80). Higher scores indicate increased levels of anxiety.

Family Assessment Device (FAD)

The short-form of the X version of the FAD[31] is a 12-item self-report measure of family functioning comprising six subscales (Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, and Behavioural Control), and an overall General Functioning scale. Mothers rated the extent to which each statement described their family functioning on a four-point scale from 1 (strongly agree) to 4 (strongly disagree). The negatively worded items were reversed and the total score corresponded to the sum of the item responses divided by the total number of items. High scores indicate worse family functioning (range=1 to 4).

Data analysis

Statistical analyses were performed using SAS software, version 9. Missing data was observed for parental education level (n=5) and marital status (n=7). Thus, data analysis was performed using the maximum number of observations available for each variable.

Student's *t*-tests, correlation analyses (Pearson's *r*) and Generalized Linear Models (GLM) were used to examine differences in mother's responses to the questionnaires according to socio-demographic and medical characteristics, as well as differences across the four domains (COM, MEDI, ROLE, EMO) of the PIP (paired *t-tests*). *T*-tests were performed to compare

mothers' responses between groups and with previous studies using the same instruments, and correlation analyses were used to examine associations between questionnaires. We considered $p<.01$ as the level for statistical significance, although we also present results of marginal significance ($p<.05$).

RESULTS

Descriptive statistics and group comparisons

Table 1 presents the socio-demographic characteristics of the sample, as well as the mean scores of the 3 questionnaires, for the whole sample and for each group separately.

Group comparisons between children diagnosed with BT and children with other ABIs indicated that the two groups were similar according to gender, age at assessment and at diagnosis, as well as mothers' age, marital status and educational level. The only difference between groups was a longer interval between diagnosis and assessment in children diagnosed with BT, compared to children with other ABIs ($t=3.17$, $p=.002$). Internal consistency values for the questionnaires were in the acceptable range, in accordance with previous reports[30-32]. Regarding the questionnaires, group comparisons indicated that there were no statistically significant differences in the PIP, the STAI and the FAD scores between the two groups.

Insert Table 1 around here

In order to assess the significance of the PIP scores in the present study, the total PIP-F and PIP-D mean scores were compared with previous reports using the same questionnaire in different clinical samples from other severe illnesses, namely children treated for Inflammatory Bowel Disease (IBD)[33] and cancer not involving the brain[29]. As seen in Table 2, the analyses indicated that the mean scores observed in the present sample of ABI patients were significantly higher than the ones observed in these two clinical populations ($t=5.2$ for

PIP-Frequency and t=12.3 for PIP-Difficulty, in the IBD sample; t=16.2 for PIP-Frequency and t=5.9 for PIP-Difficulty, in the cancer sample, p<.01 in all cases).

Insert Table 2 around here

We performed the same analyses for the STAI and the FAD. The results for the STAI indicated that the STAI-Trait mean standardized score was within the normal range (mean *T*-score=54; centile 32-69) [34], while the STAI-State score was significantly above the normal range (mean *T*-score=66; centile 94-99)[34] for 54% of the mothers included in our sample. As for the FAD, the mean scores indicated good family functioning (range: 1=best functioning to 3.8=worse functioning). The scores [M(SD)=1.8(.5)] were not significantly different from the ones obtained in a previous report using a nonclinical sample [M(SD)=1.8(.4), t=.3, p>.05][31], although they indicated better family functioning when compared to a medical sample [M(SD)=2.1(.3), t=4.4, p<.01][31].

Associations between socio-demographic characteristics and questionnaires

For children diagnosed with BT, children's age at diagnosis and mother's age were correlated with the mean Frequency scores of the PIP. Younger mothers and mothers who had children younger at diagnosis reported more frequent sources of stress (r=-.52, p=.008, n=24; r=-.54, p=.007, n=24, respectively). Supplementary analyses indicated that the mother's age was positively correlated with children's age at diagnosis and at assessment (r=.47 and r=63, respectively; p<.01, n=36), as well as with time between diagnosis and assessment (r=33, p=.05). The results of the GLM procedure indicated a significant interaction between mother's age and children's age at diagnosis. However, none of these factors were predictive of maternal reports when both variables were introduced simultaneously in the regression model.

For the other ABI group, children's age at assessment and age at diagnosis were positively correlated with the STAI mean scores (State and Trait). Mothers whose children were older at assessment and at diagnosis reached higher mean scores on the STAI-State (r=.55 and r=.54, respectively, p=.001, n=33) and the STAI-Trait (r=.47, p=.004, n=36, in both cases). The mother's age was also positively correlated with the child's age at diagnosis and at assessment (r=.64 and r=.65, p<.01, n=40). In addition, mothers with low educational levels reached higher mean scores on the STAI-Trait (t=-2.01, p=.05), and exhibited higher Difficulty scores on the PIP (t=-2.07, p=.05).

Associations between the PIP (Frequency and Difficulty), the STAI (State and Trait) and the FAD (total score)

The PIP-Frequency score was significantly correlated with all other scores, whereas the PIP-Difficulty score was significantly correlated with the PIP-Frequency, STAI-State and STAI-Trait scores, but not with the FAD score (Table 3). The STAI-State was strongly correlated with all other scores, while the STAI-Trait was moderately, albeit significantly linked to PIP-Difficulty. The FAD score was negatively correlated with all the other scores, with the exception of the PIP-Difficulty score.

Insert Table 3 around here

PIP subscales (Frequency and Difficulty) in the two groups

As seen in Table 4, the adjusted means for the Frequency and Difficulty scores were 2.62 and 3.42 (maximum=5), respectively, with total scores ranging from 2.11 to 3.18 (Frequency), and from 3.05 to 3.74 (Difficulty). The total Difficulty score was significantly higher than the total Frequency score. The results for tumors and other ABIs were equivalent between groups.

The highest value for the adjusted means was observed for the Emotional functioning domain (EMO), followed by Parental Role (ROLE), Communication (COM) and Medical care (MEDI). EMO scores were higher than scores for the other three domains. More precisely, results from paired *t*-tests showed that EMO>ROLE>COM>MEDI, $p<.0001$, $p=.004$, $p=.02$, respectively; EMO>COM, MEDI, $p<.0001$ and ROLE>MEDI, $p<.001$. For PIP-Frequency and PIP-Difficulty, the pattern of results remained unchanged, with the exception of non-significant differences observed between COM and MEDI (COM>MEDI, $p<.15$) for PIP-Frequency, and between ROLE and COM (ROLE>COM, $p=.22$) for PIP-Difficulty. In addition, results were similar when children with BT were compared to children with other ABIs.

Insert Table 4 around here

Item analysis: quantitative results

Quantitative results from the *t*-tests indicated that the four following items were significantly different between groups: "Learning upsetting news" (Other ABI>BT, $t=-2.03$, $p=.05$, for PIP-Frequency); "Watching my child have trouble eating" (BT>Other ABIs, $t=2.15$, $p=.04$ for PIP-Frequency, $t=2.10$, $p=.04$, for PIP-Difficulty); "Feeling numb inside" (Other ABI>BT, $t=-2.53$, $p=.01$, for PIP-Frequency) and "Feeling scared that my child could get very sick or die" (BT>Other ABI, $t=3.34$, $p=.01$, for PIP-Frequency).

Item analysis: qualitative results regarding the ten major stressors

The ten most prominent stressors were identified for each subscale according to the rank of their means. The first seven stressors reported in each subscale and in each group were drawn from the EMO domain. They firstly related to the mothers' worries about the future ("Worrying about the long term impact of the illness"), including the prospect of the child's

death (“Feeling scared my child could get very sick and die”). Secondly, these stressors pertained to the present situation of the sick child (“feeling helpless”, “waiting for results”). The other items that also ranked among the ten main stressors related to the ROLE domain (“feeling uncertain about disciplining my child”, “less time for the family”) and the COM-communication domain (“speaking about the illness”, “speaking with the doctor”). The medical care domain (MEDI) appeared only in the BT group (“watching my child have trouble eating”).

DISCUSSION

The present study has added to the extant literature by showing that parental stress levels are high following pediatric ABIs, regardless of the type of ABI.

These results were firstly compared to previous findings on severe illnesses other than brain injury, such as inflammatory bowel disease (IBD)[33] or cancer[29]. This comparison highlights that the PIP scores observed in the present work were significantly higher than the ones reported in case of cancer not affecting the brain, which, in turn, was superior to the PIP scores reported for IBD. These comparisons suggest that severe brain injuries are especially difficult to deal with for parents, which was corroborated in the present study by the strong association observed between mother’s reported stress and their present state of anxiety.

The intensity of parental stress following childhood ABI is consistent with previous studies in cases of pediatric brain tumor[21,11] or traumatic brain injury[3,23].

Our results evidence that socio-demographic factors, such as the age of mother' and child and the mother's education level, were both correlated to parental stress and anxiety, but differently in the two groups. More precisely, in the BT group, higher PIP-Frequency scores came from younger mothers whose children were younger at diagnosis, whereas for the other ABI group, mothers with lower educational levels had higher scores on the PIP-Difficulty item, regardless of their age. In addition, for this group, mothers of older children tended to

present increased levels of anxiety. We put forward the hypothesis that mothers of young children with BT tend to be concerned with the medical procedures relating to survival, while parents of children with other ABI tend to manifest psychological stress associated with the potential sequelae of the illness at later stages of their children's development.

The influence of socio-demographic factors in the BT group is coherent with previous reports on pediatric cancer[29]. The results from the other ABI group evidencing that maternal anxiety was linked to PIP-Difficulty for those with a lower educational level can be interpreted as pointing to a feeling of guilt, already suggested for traumatic brain injuries, known to be more frequent in lower socio-economic status[15].

The analyses of the four domains enabled the exploration of specific categories of stressors for mothers (emotional functioning, medical care, communication, parental role/function) in both groups. Emotional functioning (EMO) appeared to be the most affected domain, with maternal concerns around the child's survival and the long-term consequences of the brain injury (as demonstrated by the item analysis). The second sub-domain that emerged as a major stressor was parental role/function (ROLE), with mothers reporting difficulty educating their child ("disciplining my child"). This result strengthens conclusions from previous studies reporting the need for specialized care and follow-up for pediatric ABI survivors[6,35], since families tend to report difficulties in their ability to promote their child's autonomy[36]. Conversely, the items in the Communication (COM) and the Medical Care (MEDI) domains were not significantly reported by the mothers, suggesting that interventions might need to focus on parental emotions and educational roles, as discussed below.

The quantitative and qualitative analyses of the ten main stressors revealed differences between the two groups of participants. For the BT group, the most frequent and difficult stressors related to the life-threatening aspects of the illness. For the other group, the most

frequent and difficult stressors related to the suddenness of the injury (traumatic brain injury or stroke).

The current results suggest clinical and practical implications. The emotional burden associated with parental distress has already been alleviated with interventions like Take A Breath (TAB), shown to improve parental psychological flexibility and mindfulness[37]. The Bright Ideas, a paradigm of problem-solving program, helped mothers of children newly diagnosed with cancer, even over the long term[38]. Bright Ideas is a five step cognitive-behavioural intervention.

Regarding parental role, psychosocial interventions with parents of children with BT have the potential to strengthen parental skills in coping with the child's disabilities and in adapting to a new educational role[39].

Finally, the subdivision of the PIP subscales into Frequency and Difficulty could be useful to tailor psychosocial interventions, backed up by the clinical impression of the therapist/clinician identifying which stressor is particularly difficult even if it is not very frequent, and conversely, which stressor is frequent, but not so difficult to deal with.

Study limitations

There was significant variability in the time since diagnosis (children mostly under treatment, some with relapse, and a few in remission). A more uniform patient group would be more relevant in future studies. Moreover, a comparison group, such as mothers of children diagnosed with a severe life-threatening illness not involving the brain (e.g. severe heart disease), could favor a generalization of our results. Finally, it would be interesting to include fathers in future studies to examine whether their educational function in terms of parental style is also affected, and to what extent.

CONCLUSION

The present study highlights the importance of assessing maternal stress in children with severe ABI. The comparison between those with brain tumors and those with other brain injuries yielded important similarities but also some differences. The PIP instrument captured patterns of distress experienced by mothers, especially those relating to their emotional functioning and parental role. Stress levels were found to be comparable between groups, although the item analyses distinguished different stressors for each group.

Clinical implications

This assessment tool for maternal stress in case of severe pediatric ABI could improve the assessment of this important aspect, and lead to specific targeted interventions, such as the TAB[37] or Bright Ideas[38].

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Table caption

Table 1. Descriptive statistics of the study variables

Table 2. Comparisons between the PIP mean scores (Frequency and Difficulty) with those for inflammatory bowel disease or cancer (not involving the brain)

Table 3. Pearson's correlations between the PIP (Frequency and Difficulty), the STAI (State and Trait) and the FAD (Total score)

Table 4. Adjusted means for the 4 domains in the PIP (Frequency and Difficulty) for the two groups

Table 1

Descriptive statistics of the study variables

	Total *n*=78		Tumors *n*=37		Other ABI *n*=41	
	M(SD)	**N(%)**	**M(SD)**	**N(%)**	**M(SD)**	**N(%)**
Mothers						
Age	39.2(6.4)		39.3(5.9)		39.1(6.8)	
Marital status						
Married/living with partner		58(82.9)		29(90.6)		29(76.3)
Divorced/widowed/single		12(17.1)		3(9.4)		9(23.7)
Educational level						
High		37(50.7)		17(51.5)		20(50)
Children						
Gender						
Male		49(62.8)		21(56.8)		28(68.3)
Age at assessment (years)	9.3(5.1)		9.9(5)		8.8(5.2)	
Age at diagnosis (years)	7.7(5)		7.3(4.8)		8.1(5.3)	
Time since diagnosis (years)	1.5(2.2)		2.3(3)		.8(.5)	
Currently under treatment		36(46.2)		21(56.8)		15(36.7)
Motor or cognitive sequelae		44(56.4)		20(54.1)		24(58.5)
Questionnaires						
PIP-F	110.2(25.8)		105.6(27.6)		114(24.1)	
PIP-D	143.7(31.1)		141.8(36.3)		145.4(26.1)	
STAI-T	48.1(12.1)		46.7(11.2)		49.5(12.9)	
STAI-S	52.4(14.7)		52.2(14.8)		52.5(14.8)	
FAD	1.8(.5)		1.7(.5)		1.9(.5)	

PIP-F: Pediatric Inventory for Parents-Frequency; PIP-D: Difficulty; STAIT-T: State-Trait Anxiety Inventory-Trait; STAI-S: State; FAD: Family Assessment Device.

Table 2

Comparisons between the PIP mean scores (Frequency and Difficulty) with those for inflammatory bowel disease or cancer (not involving the brain).

		ABI	IBD	Cancer
PIP-Frequency	**M(SD)**	110.2(25.8)	84.4(27.9)**	94(33.3)**
PIP-Difficulty	**M(SD)**	143.7(31.1)	78.2(25.2)**	112.4(35.1)**

ABI: Acquired Brain Injury, current study; IBD: Inflammatory Bowel Disease[35]: *n*=62; Cancer [29]: *n*=126; PIP: Pediatric Inventory for Parents; M: Mean; SD: Standard Deviation; ***p*<.01: mean comparisons (student's *t*-test) of ABI with IBD and cancer.

Table 3

Pearson's correlations between the PIP (Frequency and Difficulty), the STAI (State and Trait) and the FAD (Total score).

	PIP-F		PIP-D		STAI-T		STAI-S	
	n	*r*	*n*	*r*	*n*	*r*	*n*	*r*
PIP-F								
PIP-D	50	.42**						
STAI-T	50	.52***	50	.33*				
STAI-S	50	.63***	51	.53***	66	.77***		
FAD	51	-.42**	51	.03	70	-.46***	66	-.33**

*p<.05; **p<.01; ***p< .001; *n*: number of participants; *r*: Pearson's correlation coefficient; PIP-F: Pediatric Inventory for Parents-Frequency; PIP-D: Difficulty; STAIT-T: State-Trait Anxiety Inventory-Trait; STAI-S: State; FAD: Family assessment Device.

Table 4

Adjusted means for the 4 domains in the PIP (Frequency and Difficulty) for the two groups

	Total		**Tumors**		**Other ABIs**	
	***n*=65**		***n*=30**		***n*=35**	
	PIP-F	**PIP-D**	**PIP-F**	**PIP-D**	**PIP-F**	**PIP-D**
	M(SD)	**M(SD)**	**M(SD)**	**M(SD)**	**M(SD)**	**M(SD)**
COM	2.24(.60)	3.26(.89)	2.23(.65)	3.20(.95)	2.26(.56)	3.31(.85)
MEDI	2.11(.67)	3.05(1.04)	2.01(.67)	3.12(1.11)	2.20(.67)	3.00(.99)
ROLE	2.72(.77)	3.16(.78)	2.58(.81)	3.23(.89)	2.84(.73)	3.10(.68)
EMO	3.18(.82)	3.74(.70)	3.08(.81)	3.71(.79)	3.27(.82)	3.78(.63)
Total	2.62(.61)	3.42(.73)	2.51(.66)	3.38(.87)	2.71(.57)	3.46(.62)

Higher scores indicate increased levels of parental stress (maximum=5); *n*: number of participants; M: adjusted mean; SD: Standard Deviation; PIP-F: Pediatric Inventory for Parents-Frequency; PIP-D: Difficulty; COM: Communication; MEDI: Medical Care; ROLE: Role function; EMO: Emotional function.