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Maternal Stress and Paediatric Brain Cancer: a French study

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MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

Abstract

Background: Despite evidence that paediatric cancer induces a trajectory of parental stress, studies in case of childhood malignant brain tumours remain scarce. The present work aims to add to the scientific literature by evaluating maternal stress with a French translation of the Paediatric Inventory for Parents (PIP) in a population of mothers whose children have been diagnosed with a brain tumour.

Procedure: The mothers of 35 children with malignant brain tumours completed the Paediatric Inventory for Parents (PIP), the State-Trait Anxiety Inventory (STAI) and the Family Assessment Device (FAD) at a mean time since diagnosis of 2.3 years.

Results: The PIP showed good internal consistency and correlated significantly with the STAI and the FAD. Maternal stress scores were higher in younger mothers and in mothers of younger children. Emotional functioning was the most affected domain.

Conclusions: Emotional stress as assessed by the PIP in mothers of children with malignant brain tumours is considerable, and should be routinely assessed, in order to implement appropriate specific psychosocial interventions when needed.

Keywords: Maternal Stress, Paediatric Brain Tumours, Assessment, Standards of Care.

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER**Maternal Stress and Paediatric Brain Cancer: a French study**

In France, an estimated one out of every 440 children is diagnosed with cancer before the age of 15, the most frequent paediatric cancers being leukaemia (29%), central nervous system tumour (23%), lymphoma (12%) and neuroblastoma (8%)¹. Between 2000 and 2008, the overall survival was 91.7% at 1 year, 86.9% at 2 years and 81.6% at 5 years² for paediatric cancers in general, and 84.3% at 1 year, 77.5% at 2 years and 71.9% for Central Nervous System (CNS) malignancies, such as brain tumours. Given the lack of studies on parental stress in case of paediatric cancer in France³, the present study aimed to evaluate parental, and here maternal stress using the Paediatric Inventory for Parents (PIP)⁴ in a population of French mothers whose children had been diagnosed with a brain tumour. **Indeed, since mothers are more frequently present than fathers during the medical visits for paediatric cancer, only mothers have been envisaged in this study.**

Childhood cancer is a highly stressful experience for the family, including the child, his/her parents and the siblings⁵⁻¹³. Paediatric cancer generates a trajectory of stress from the diagnostic announcement throughout treatment, remission and possible relapses¹⁴. The psychological repercussions on parents of children diagnosed with cancer, such as anxiety or depression, are considerably greater compared to other paediatric illnesses^{7,13}. Because parental and child mental health are interconnected¹⁵, the need to support parental mental health has long been considered essential¹⁶. Indeed, parental stress is an important dimension of parental mental health, since parents frequently experience psychological difficulties in the presence of serious health problems in their child¹⁷⁻¹⁹, even if several factors, such as family functioning, can be protective²⁰. This issue has recently led researchers to propose the Psychosocial Standards of Care for Childhood Cancer based on a systematic literature review focused particularly on parents of children with cancer²¹. **An important recommendation is**

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

the assessment of parental mental health, in order to define and implement appropriate interventions according to needs.

The large majority of studies on parental stress consider paediatric cancers in general. However, children with brain tumours have to face particular treatments (neurosurgery, chemotherapy, and/or high-dose central nervous system irradiation) and treatment-related sequelae, both physical and neurocognitive (including impaired health, endocrine deficits, cognitive deficits, learning difficulties) ²¹⁻²⁷. These specific sequelae of brain injury have significant long-lasting impact on the child's academic achievement, independence, social integration and overall participation in society. In addition, research has mainly focused on treatment risk and less on the role of family concerns ²⁸. For instance, parents of children with brain tumours not only feel distressed about their child's later school achievement after recovery ²⁹, they also face also long-term uncertainty and the burden of caregiving, even when their children are off treatment ³⁰. Overall, there is not enough research addressing stress among mothers of children with brain tumours, which account for 30 % of paediatric cancers in France ¹.

The assessment instruments for evaluating maternal stress generally do not take into account the **particularities** of paediatric cancer ³¹, even less in the case of brain cancers which generate parental concern on two counts: the impact of cancer, on the one hand, and of the brain injury on the other. In the present study, we opted to use the Paediatric Inventory for Parents (PIP ⁴) as a measure of maternal stress. Although this questionnaire was not specifically developed for paediatric cancer, it was elaborated to evaluate parental stress related to severe illnesses and malignancies (*e.g.* leukaemia, lymphoma), and designed to explore specific categories of extreme stressors for parents (emotional functioning, medical care, communication, role function). Results from studies performed using the PIP have highlighted associations of parental stress with parental anxiety⁴, and aspects of family

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

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3 functioning such as communication, family roles and affective responsiveness¹². Further, the
4 PIP was identified as one of the few assessment instruments currently available to evaluate
5 parental stress related to paediatric cancer in a recent literature review³. For these reasons, we
6 considered the PIP the most suitable instrument to evaluate maternal stress in the present
7 work.
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METHODS

Participants

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18 Participants were selected from two hospitals near Paris specialized in the treatment of
19 paediatric cancers (Gustave Roussy) and in the rehabilitation and follow-up of children with
20 acquired brain injury, including brain tumours (Saint Maurice Hospital). Inclusion criteria
21 were having a malignant brain tumour at least one month from diagnosis and, for the mothers,
22 being able to understand, speak and read French. Of the 48 eligible mothers who were
23 approached, 35 gave their informed consent and participated in the study, which provided a
24 participation rate of 73 %. All questionnaires were rendered anonymous in order to keep data
25 analysis confidential.
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35 The mean age of the 35 children (19 boys, 16 girls) was 9.9 years (SD = 5.1 years, range 2.5 –
36 22 years). The mean time since diagnosis was 2.3 years (SD = 3.05, range: 2 months-14
37 years). At the time of the study, 20 children were under treatment and 15 had finished their
38 treatment.
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Procedure

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46 The study was approved by the medical ethics committees at both participating institutions.
47 Eligible mothers received information about the study and a consent form. They were
48 contacted on the occasion of a medical consultation either by the treating physician or by the
49 researchers. The mothers could complete the questionnaires directly in the waiting room of
50 the hospital or complete them later at home and send them back by post. In both cases, the
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MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

questionnaires and aims of the study were explained to them. In addition, medical data was obtained from clinical report forms addressed to the physicians and sociodemographic data was obtained through the hospital medical reports by the researchers.

Measures

In addition to the PIP, the mothers were invited to complete two other questionnaires to assess the construct validity of the French version of the PIP, namely the State Trait Anxiety Inventory (STAI) and the Family Assessment Device (FAD). Both tools have been found to be correlated with the PIP evaluation^{12,32}.

PIP

The PIP is a 42-item self-report questionnaire that measures parental stress. It comprises four domains: Communication with the child and the medical team (COM, 9 items; e.g. 'Speaking with the doctor'), Medical Care (MEDI, 8 items; e.g. 'Helping my child with medical procedures (having injections, swallowing medicine, changing dressings)'), Parental Role (ROLE, 10 items; e.g. 'Feeling uncertain about disciplining my child') and Emotional Functioning (EMO, 15 items; e.g. 'Worrying about the long-term impact of the illness').

Each of the 42 items is rated on two 5-point Likert-type Scales, one assessing the frequency of each stressor during the last week, and one assessing how difficult the issue has been for them as a parent.

The English-language PIP has recently been rated 6 on a 7-point level of evidence scale³³ and is a well-known tool present in reviews on family changes in case of childhood cancer^{9,21}.

Translation of the PIP into French. After contacting the first author of the PIP, this questionnaire was translated into French by a team of three people. An English native speaker was asked to perform a back translation. The translated version was pilot-tested with 20 families who were invited to point out any items that might be difficult to understand, so as to change the wordings if required. No adaptation proved necessary.

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER***STAI***

The French version of the State-Trait Anxiety Index³⁴ is a 40-item questionnaire assessing the respondent's present state of stress (State, 20 items) and his or her general inclination toward anxiety (Trait, 20 items). The STAI has high internal consistency and appropriate construct and discriminative validity across typically-developing and clinical samples³⁵, including families of childhood cancer survivors³⁶. The mothers were asked to rate each statement on a four-point scale ranging 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.

FAD

The short form of the French version of the Family Assessment Device (FAD)³⁷ 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. Previous research has demonstrated the adequacy of the psychometric properties of the FAD and its usefulness as a measure of family functioning in nonclinical and medical samples^{37,38}, such as in the case of pediatric cancer⁵. In the present study, the mothers were solicited to rate the extent to which each statement described their family functioning on a four-point scale ranging from 1 (strongly agree) to 4 (strongly disagree).

Data analysis

Statistical analyses were performed using SAS software, version 9. Missing data was observed for some variables of interest, namely parental education level and marital status ($n=3$). For this reason, the analyses described hereafter were performed with the maximum number of observations for each variable included in the analyses and are reported in each table. For the FAD, the total score corresponded to the difference between the sum of the positive worded items and the sum of negative worded items, with higher scores indicating better family functioning (maximum score =18). For the STAI, we computed a total score by

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

1
2 summing the items of the Trait and the State scales (maximum score for each scale= 80), with
3
4 lower scores indicating reduced levels of anxiety. For the PIP, Frequency and Difficulty
5
6 subtotal scores were obtained by summing the items that composed each subscale (maximum
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8 total score = 42). In addition, we adjusted on the mean values for each subscale by dividing
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10 the sum of responses to each subscale item by the total number of items composing the
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12 subscale, which rendered the mean values between subscales comparable. For educational
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14 level, we generated a binary variable defining whether the mother's current occupation
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16 required the completion of a high school diploma (high) or not (low). We opted to define
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18 parental educational level based on the mother's current occupation, as sociodemographic
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20 information was collected through the hospital's medical records, containing only the register
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22 of the mother's occupation.
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26 *T*-tests, correlation analyses (Pearson's *r*) and Generalized Linear Models (GLM) were used to
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28 examine differences in the responses to the questionnaires according to socio-demographic
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30 and medical characteristics of the mother and the child, as well as differences across the four
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32 domains (COM, MEDI, ROLE, EMO) in each subscale (paired *T tests*). Correlation analyses
33
34 were also used to examine associations between questionnaires. We considered $p < .01$ as the
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36 level required for statistical significance, although we also present results of marginal
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38 significance ($p < .05$).
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RESULTS**Demographic characteristics**

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45 Mother and child demographic characteristics (see Table 1) were examined in relation to the
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47 PIP responses by computing *t*-tests and correlations across variables. The Frequency subscale
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49 score on the PIP was associated with maternal age (higher scores for younger mothers: $r = -$
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51 $.52$, $p = .011$) and with the child's age at diagnosis (higher scores for younger children: $r = -$
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53 $.53$, $p = .009$). No other significant differences were observed in the mothers' responses to the
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MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

PIP, (either for the Frequency or the Difficulty subscale scores) according to the mother and the child's socio-demographic characteristics.

Construct validity of the PIP

Correlations across the four subscales of the PIP varied from .46 to .74 for the Frequency dimension and from .70 to .86 for the Difficulty dimension.

Internal consistency values for these subscales were in the acceptable range (α ranging from .63 to .93, see Table 2), as were the reliability indexes for the subscale scores for Frequency and Difficulty ($\alpha=.87$ and .93, respectively).

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

PIP-Frequency was significantly correlated with all other scores, whereas the PIP-Difficulty was only significantly correlated with PIP-Frequency and STAI-State (see Table 3). The correlation between STAI-Trait and STAI-State was strong. The FAD was negatively correlated with the STAI-T.

Subscales in the PIP

As presented in Table 2, adjusted means (on the number of items) for the subscale scores ranged from 2.01 to 3.08 for the responses pertaining to Frequency, and from 3.05 to 3.67 for the responses indicating the degree of Difficulty. The subscale adjusted means for Frequency and Difficulty were 2.48 and 3.36, respectively.

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). The total Difficulty score was significantly higher than the total Frequency score.

EMO scores were higher than scores for the other three domains (see table 2 for more details).

Item analysis: the ten major stressors among French mothers

For each subscale (PIP-F, PIP-D), we identified the ten most prominent stressors according to the rank of their means. Table 4 shows that the first eight stressors in each subscale concern

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

1 the EMO domain. Five of the first ten stressors were the same in the two subscales. They
2 firstly relate to mothers' worries about the long-term impact of the illness and the future (rank
3 1 for both scales, ranks 3 and 5 for Frequency and Difficulty, respectively), including the
4 prospect of the child's death (ranks 2 and 3 respectively). Secondly, these stressors pertain to
5 the present situation of the sick child ('feeling helpless', ranks 4 and 6 respectively, 'waiting
6 for results', ranks 8 and 10 respectively).

7
8 The other stressors that also ranked in the first ten places (out of 42 items) relate to the ROLE
9 domain ('disciplining the child' ranks 9 for Frequency, 'less time for the family' ranks 9 for
10 Difficulty) and the COMMunication domain ('speaking about the illness' ranks 10 for
11 Difficulty). The domain of medical care does not appear in this ranking.

DISCUSSION

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13 Parental stress has recently been conceptualized as a fundamental dimension of mental health
14 in the recommendations for psychosocial care of parents with children diagnosed with cancer,
15 because of the significant psychological difficulties frequently experienced by parents^{7,13}.
16 Because parental stress associated with paediatric brain cancer has been shown to have an
17 impact on specific concerns linked to both survival and brain injury, the assessment of stress
18 in the present work was performed on a French population of mothers whose children had
19 been diagnosed with a brain tumour.

20
21 Our results indicated that the Frequency and Difficulty subscales of the PIP were significantly
22 correlated, and PIP internal consistency was acceptable. These results corroborate the findings
23 of previous studies performed in other countries^{4,32} (for results with American and Dutch
24 samples, respectively). Interestingly, in our study, focused on children with brain tumours, the
25 Frequency and Difficulty subscale scores tended to be higher than those observed in the
26 abovementioned studies^{4,32}, especially for the Difficulty subscale (although no statistical
27 analyses were performed). This result could suggest that mothers of children with brain
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MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

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3 cancer might indeed experience greater levels of stress due to the severe implications of the
4 brain injury and its treatment, in addition to those of cancer per se, when compared with other
5 cancers. This particular finding underlines the **relevance** of the PIP as an assessment
6 instrument to evaluate parental stress in paediatric brain cancer, and suggests that it might
7 allow **for discrimination** between discrete levels of parental stress according to distinct
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paediatric conditions.

The PIP scores, especially on the Frequency subscale, were correlated with anxiety and family functioning scores, meaning that maternal stress overlaps with anxiety and a lack of general wellbeing in the family. These results are in line with earlier findings ⁴ and also validate the PIP as a measure of stress in specific disease-related situations. It should be noted that in the present study the FAD was strongly negatively-correlated with the STAI-Trait, suggesting that the general tendency towards anxiety observed among mothers might be linked to family cohesion.

The four domains of stress (communication, medical care, parental role and emotional functioning) did not seem to be affected to the same degree in this sample of mothers of children with malignant brain tumours, which confirms our hypothesis that some stressors may be typical of paediatric brain cancer. More precisely, the emotional domain (EMO) appeared to be the most affected, with maternal concerns about survival and the long-term consequences of the brain injury (as demonstrated by the item analysis). For instance, a young mother of a 2-year-old child related informally how the announcement of her child's brain tumour was so hard that she had a miscarriage at 7 months of pregnancy (this exchange was not part of the questionnaire). Worrying about the child's future and feeling helpless over the child's condition reflects parental concern regarding the child's autonomy and learning, areas that tend to be significantly impacted by brain tumours ^{25,27,39,40}. Parental emotion focused

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

1 coping has also been found to be linked to high level of stress in caregivers of children with
2 brain tumours⁴¹.
3

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5 Together with the Emotional domain (EMO), parental role (ROLE) appeared to be more
6 affected than the communication and the medical care domains in the Frequency subscale.
7
8 The item analysis revealed that maternal concerns were mostly about “time for herself”, but
9 also for the other family members. A similar result was also found as the first concern
10 mentioned by parents in paediatric cancers³⁹.
11

12
13 Another subdomain that emerged as a major stressor in the parental role (ROLE) domain was
14 the difficulty educating the child (“disciplining the child”), i.e. maintaining parental function.
15 This result is congruent with previous studies⁴⁰ concerning the need for aftercare for
16 paediatric brain tumour survivors, whose families reported difficulties in their ability to
17 encourage autonomy in their child⁴⁰ and the tendency to be overprotective⁹. This particular
18 finding is also in line with clinical observations regarding some parents who are able to lower
19 their expectations regarding their child's academic success, because they are aware that the
20 brain tumour might impair his/her learning. Results about the parental role as a major stressor
21 are congruent with those about the role of parental cognitions like parental (external) locus of
22 control in caregivers of children with brain tumours⁴¹.
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38 It is important to note that the PIP-Frequency score was linked to maternal age, with older
39 mothers reporting less stress than younger ones, in agreement with previous results⁴. We can
40 hypothesise that older mothers may have better knowledge on the subject of brain tumours, as
41 well as more experience in coping with their child's illnesses. Additionally, these "older
42 mothers" might **gain the most benefit** from social support networks. In agreement with the
43 abovementioned previous study, the PIP scores were not linked to marital status nor to
44 educational level, but to the child's age at diagnosis, with mothers of younger children
45 reporting more stress than mothers of older children.
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MATERNAL STRESS AND PEDIATRIC BRAIN CANCER**Limitations**

The number of participants was small and we were not able to investigate if the non-respondent mothers were less educated and less able to answer written instructions. Another limitation concerns the significant variability of time since diagnosis, which should be taken into account. Maternal stress was assessed here for children who were mostly under treatment, some with relapse, and a few in remission. Given that maternal stress may be impacted by the history of the illness, a more uniform patient group (e.g. immediately after the diagnosis, just after the end of the treatment, some years after the end of treatment) would be more relevant in future studies. In addition, the lack of normative data, and of a comparison group, limits the extent to which our results can be interpreted in relation to normative and/or clinical populations.

Clinical implications

The clinical and practical implications of the present results are noteworthy. The subdivision of the PIP subscales into Frequency and Difficulty, each subdivided into four domains, could be useful to tailor psychosocial interventions, backed up by the clinical impression of the therapist/clinician assessing the situation. As the emotional domain (EMO) and the parental role (ROLE) domain appeared to be major stressors for mothers, emotional distress calls for psychological interventions, while parental role difficulties could warrant social interventions.

Previous studies have underlined the fact that psychosocial interventions among parents of children with cancer, especially brain tumour survivors, and aimed at strengthening parental skills in coping with their children's disabilities, have the potential to reduce parental stress^{41,43} and to reinforce family quality of life following the completion of treatment⁴⁴. The present study on maternal stress suggests that interventions targeting the reduction of emotional distress might also help mothers during the child's treatment.

Conclusion

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

1
2 The present study confirms the importance of assessing maternal stress in children with
3 malignant brain tumours using an instrument that captures the specific patterns of distress
4 experienced by these caregivers, in terms of emotional functioning and parental role. The
5 French PIP appears **to be** valid assessment tool to gain insight into stress experienced by
6 mothers in the course of their child's illness. Scores for stress on the PIP could help to
7 develop specific interventions. As evidenced in recent research, psychosocial interventions
8 among parents of children with cancer, especially brain tumour survivors, can strengthen
9 caregiver competence and family functioning following the completion of treatment⁴⁵.

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MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

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MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

Table caption

Table 1. Demographic characteristics of mothers and children.

Table 2. Adjusted means of the 4 PIP subscales and internal consistency of the 2 subscale scores (Frequency and Difficulty).

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

Table 4. The first ten stressors in each of the French PIP subscales.

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MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

Table 1

Demographic characteristics of mothers and children.

	M (SD)	N (%)
Mothers		
Age	39.4 (5.9)	35
Marital status		
<i>Married/living with partner</i>		29 (91)
<i>Divorced/widowed/single</i>		3
Educational level		
<i>High</i>		16 (50)
<i>Low</i>		16 (50)
Children		
Gender		
<i>Male</i>		19 (54)
<i>Female</i>		16 (46)
Age at assessment (years)	8.9 (5.1)	
Age at diagnosis (years)	7.4 (4.9)	
Time since diagnosis (years)	2.3 (3.0)	
Siblings		
<i>No sibling</i>		0
<i>1 sibling</i>		6
<i>2 or more siblings</i>		26 (81)
Relapse (Yes)		9 (26)
Under treatment (Yes)		20 (57)
Motor or cognitive sequelae (presence)		19 (54)

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

Table 2

Adjusted means of the 4 PIP subscales and internal consistency of the 2 subscale scores (Frequency and Difficulty).

	French (N=34)			
	PIP-F		PIP-D	
	M	α	M	α
COM	2.22	.71	3.22	.80
MEDI	2.01	.63	3.05	.85
ROLE	2.59	.79	3.18	.77
EMO	3.08	.86	3.67	.87
Total	2.48	.87	3.36	.93

PIP-F: Frequency; PIP-D: Difficulty; N: number of participants; M: adjusted mean; α : Cronbach's coefficient

Results from paired *T* tests showed that EMO > MEDI, COM, $p < .0001$; EMO > ROLE, $p < .001$; ROLE > MEDI, COM, $p < .001$ for PIP-F; for PIP-D, *T* tests showed that EMO > MEDI, ROLE, COM, $p < .001$.

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER**Table 3**

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

	1		2		3		4	
	<i>N</i>	<i>r</i>	<i>N</i>	<i>r</i>	<i>N</i>	<i>r</i>	<i>N</i>	<i>r</i>
1. PIP-F								
2. PIP-D	23	.46*						
3. STAI-T	22	.49*	23	.25				
4. STAI-S	22	.64**	23	.48*	32	.71***		
5. FAD	22	-.44*	23	.03	33	-.55***	32	-.31

* $p < .05$; ** $p < .01$; *** $p < .001$; *N*: number of participants; *r*: Pearson's coefficient of correlation.

MATERNAL STRESS AND PEDIATRIC BRAIN CANCER

Table 4

The first ten stressors in each subscale of the French PIP.

PIP-Frequency			PIP-Difficulty		
Rank	Stressors	Domain	Rank	Stressors	Domain
1	Worrying about the long-term impact of the illness	EMO	1	Worrying about the long term impact of the illness	EMO
2	Feeling scared that my child could get very sick or die	EMO	2	Knowing my child is hurting or in pain	EMO
3	Feeling uncertain about the future	EMO	3	Feeling scared that my child could get very sick or die	EMO
4	Feeling helpless over my child's condition	EMO	4	Seeing my child sad or scared	EMO
5	Seeing my child's mood change quickly	EMO	5	Feeling uncertain about the future	EMO
6	Thinking about other children who have been seriously ill	EMO	6	Feeling helpless over my child's condition	EMO
7	Difficulty sleeping	EMO	7	Thinking about my child being isolated from others	EMO
8	Having little time to take care of my own needs	ROLE	8	Waiting for my child's test results	EMO
9	Feeling uncertain about disciplining my child	ROLE	9	Trying to attend to the needs of other family members	ROLE
10	Waiting for my child's test results	EMO	10	Speaking with doctor	COM

The stressors common to both subscales are in **bold**.