



# The burden of parenting children with frontal lobe epilepsy

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## ABSTRACT

**Objective:** Caring for a child with a chronic illness adds stress to the typical parenting stress in healthy developing children. This stress can place a heavy burden on parents and may increase when a child displays problem behavior. In general, parenting and child's behavior problems are associated. Furthermore, externalizing (more outgoing) behavior is reported frequently in children with frontal lobe epilepsy (FLE). Therefore, in this study, we first investigated the burden of parents of children with FLE, and second, we investigated the relation between the experienced burden and reported behavioral problems. The validity of parents' reports on proxy measures as well as duration of epilepsy is taken into account.

**Methods:** Thirty-one parents of children with FLE completed validated questionnaires about behavioral problems and burden of parenting. To examine if parents tend to be inconsistent or unusually negative, we used the two validity scales of the Behavioral Rating Inventory of Executive Function (BRIEF) (Negativity and Inconsistency).

**Results:** Only parents of children with FLE who have had epilepsy for 5 years or longer report more problems on the Nijmeegse Vragenlijst voor de Opvoedingssituatie (NVOS) subscales 'Able to manage', 'Child is a burden', and 'Good Interaction' compared with the healthy controls. The subscale 'Child is a burden' significantly predicts scores in about 20% to 49% on the main scales of the Child Behavior Checklist (CBCL), the Global Executive Composite (GEC), and Behavioral Regulation Index (BRI) of the BRIEF. Only 6% of parents scored in the clinical range of the negativity scale of the BRIEF. For the inconsistency scale, this was 45%.

**Conclusion:** Parents of children with FLE do not report excessive parental burden. Longer duration of epilepsy might be a risk factor in experiencing burden. The findings suggest a link between parental burden and behavioral problems in children with FLE. Externalizing behavioral problems are the most marked behavioral problems, which relate to the parental burden. Parents tend to be inconsistent in their ratings.

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## 1. Introduction

Childhood chronic illness often impacts the entire support system [1,2], which in return influences health and health outcomes of children (e.g., [3]). Parenting stress is a key issue [1,4–7].

Family factors are recognized to be strong predictors of behavior problems in children with epilepsy [8–10], for instance, parenting style [8–12], and caregiver psychopathology [13].

Epilepsy-related factors that have a role in the development of parental stress are the uncertainty about seizure occurrence, potential complications, and uncertainty about long-term outcome [14,15]. The comorbid cognitive disabilities [16–18] may also contribute [15, 19–22]. Further, healthcare issues have been mentioned, such as seizures management, clinic visits, health decline, and hospitalizations. Lifestyle issues to maintain seizure control, for example, sleep management and restricted family activities, may also contribute to the parents' burden.

Lastly, children's behavioral problems are an important factor leading to parental stress and depression [1,8,23]. These behavioral problems are more common in epilepsy than in other chronic conditions [14,24–30] and might be caused by the underlying brain pathology and its dynamics [31–33]. A predisposition for developing behavioral problems [34], and even a bidirectional relationship between behavioral disorders and epilepsy have been suggested [35,36].

In sum, epilepsy affects parenting and a child's behavior, leading to parenting stress and burden. This, in turn, affects the child's behavioral problems (Fig. 1). It could be argued that behavior as well as parenting might interact with epilepsy factors. Different definitions of burden (or family stress) have been proposed in the literature, and they all emphasize the effect (living with) a patient has on the family. We operationalize the parental burden in this study as added stress on the parent and family caused by the pediatric chronic illness. This is an additional challenge to the typical parenting role, which naturally presents occasional stressors throughout development [37].

Externalizing behavioral problems are often reported in children with FLE (e.g., [38,39]). This is in contrast to the marked internalizing behavioral problems in focal temporal seizures [9,10]. Focal frontal

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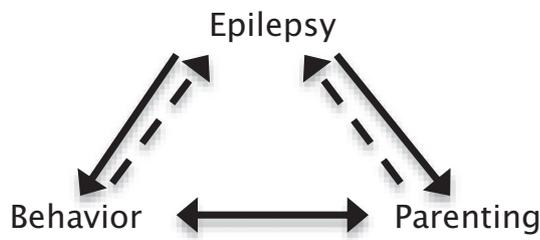


Fig. 1. Interaction epilepsy, behavior and parenting.

seizures are associated with nocturnal seizures [40–42] and possible executive dysfunction [43,44], which are related to behavioral problems (e.g., [44]). Furthermore, it is assumed that externalizing behavioral problems place a greater burden on the caregiver [45,46]. Therefore, the aim of the present study was twofold. First, we want to investigate the burden of parents of children with frontal lobe epilepsy (FLE). This subject has not previously been investigated in this group and is of general interest as it is relevant to the clinical practice in order to develop adequate interventions.

Second, we aim to investigate the relationship between the experienced burden and reported behavioral problems. Additionally, we will explore the difference between more externalizing (outgoing) behavior and more internalizing (introvert) behavior in relation to the experienced burden. Most research is based on parent and/or teacher-proxy measures. An instrument often used and validated in the field is the child behavior checklist (CBCL) [24,25,47–49]. As responses of caregivers may be inaccurate or exaggerated [9–11,14,28,50–53], also due to parenting stress, the validity of parent-proxy measures might be questioned. For this reason, the validity of parents' reports on proxy measures will be taken into consideration. Lastly, most epilepsy variables do not seem to be of much influence on cognitive development (e.g., [38]). However, studies show that longer duration of epilepsy might be considered a risk factor for developing psychopathology (e.g., [44]). As children's behavioral problems can lead to parental stress, duration of epilepsy might also be a risk factor for increased parental burden. Therefore, we will also investigate duration of epilepsy in relation to parental burden.

## 2. Methods & materials

### 2.1. Sample

This study was part of a larger study concerning executive and behavioral functioning in children with FLE. For this study, all children aged 8 to 12 years with a confirmed diagnosis of FLE were referred by the pediatric neurologist between January 2013 and January 2015 for assessment to the psychology department of our tertiary epilepsy center. Some of these children were referred because parents reported cognitive and/or behavioral problems, but a large proportion was referred on behalf of this study. Children with FLE who were assessed prior to January 2013 and who met the inclusion criteria were invited to participate also. There were 5 children of 7 years old included because they almost turned 8. Parents completed questionnaires concerning the burden of parenting and perceived behavioral problems while children were being tested. As all included patients were Dutch native speakers, all communication was done in Dutch and all questionnaires were validated in Dutch.

The diagnosis focal frontal epilepsy was based on the International League Against Epilepsy criteria and confirmed by an electroencephalogram (EEG) recording. The frequency of seizures was unfortunately unknown, partly because a large part of the sample experienced nightly seizures, which are difficult to detect.

Inclusion criteria were age between 8 and 12 years because assessment of executive functioning with validated and normative tests is

possible from the age of eight. Besides, executive function demands differ in primary and secondary education, and in the Netherlands, children attend secondary education from approximately age twelve. Moreover, previous work [54] has shown significantly poorer performance in children with FLE aged 8–12 years compared with other children with other epilepsies. Other inclusion criteria were intelligence quotient (IQ) > 70 or school achievement scores above C level (Dutch CITO) in math and language in order to understand test assessment. We excluded children with psychiatric problems, which could influence test assessment, meaning not being cooperative or having problems adjusting to the test structure, except for attention-deficit and hyperactivity disorder (ADHD), which is common in children with epilepsy [55].

The study was approved by the Ethical Committee of Medisch Spectrum Twente (MST) Enschede, and parents gave their informed consent.

### 2.2. Measures

#### 2.2.1. Parents' burden

The main scale A with 8 subscales (see Table 1) of the Dutch questionnaire Nijmeegse Vragenlijst voor de Opvoedingssituatie (NVOS) [56] was used to measure the burden of parents. This scale represents only the experienced burden. Internal consistency and test–retest reliability are good [56]. The questionnaire is validated with different control groups. The manual of the NVOS shows normative data for the different scales in the main subscales for several norm groups. Our group was only compared with a healthy control group.

#### 2.2.2. Behavior problems

Parents completed the Child Behavior Checklist (CBCL) [49] and the Behavioral Rating Inventory of Executive Function (BRIEF) [57] (Table 1). This analysis focuses on the externalizing and internalizing scale of the CBCL and the two main indices (Behavioral Regulation Index (BRI) and Metacognition Index (MC)) and general index (Global Executive Composite (GEC)) of the BRIEF.

The BRIEF has good psychometric properties that include appropriate construct validity. Internal consistency is strong, and the test–retest reliability is also high [58]. The validity of the parent scores was explored using the two validity scales of the BRIEF: “Negativity” and “Inconsistency”. The first estimates whether responses are given in an unusually negative way. The latter estimates whether responses are inconsistent. A ‘Negativity’ and ‘Inconsistency’ score  $\geq 5$  is considered statistically significant. A score 1.5 standard deviation (SD) ( $\geq$  percentile 93) above average is considered statistically significant for the indices.

The CBCL is a well-established behavioral questionnaire with good psychometric properties [49], also for children with epilepsy [48]. A score 1.33 SD ( $\geq$  percentile 90) above average is considered statistically significant for the main scales.

### 2.3. Statistical analysis

Data were analyzed using the Statistical Package for Social Sciences (IBM SPSS Statistics 23.0). The data were compared with normative data of the Dutch population. To explore group differences based on duration of FLE, children were categorized into short (<5 years) vs long ( $\geq 5$  years).

Data of the NVOS were calculated and compared with the normative data. Effect sizes for these data are shown using Cohen's *d*.

The association between the NVOS and the behavioral scales was investigated with the Spearman's rank-order correlation. Simple univariable and multiple regressions were used to evaluate the relationship between the NVOS scores and the scores on the behavioral scales. To differentiate between ‘outgoing behavior’ and ‘introvert behavior’, we grouped the externalizing scale of the CBCL and the BRI of the BRIEF for outgoing behavior and the internalizing scale of the CBCL and the MC of the BRIEF for introvert behavior.

**Table 1**  
Test protocol.

Test	Description
Nijmegense Vragenlijst voor de Opvoedingssituatie (NVOS)	A questionnaire to assess burden of parenting and attributions towards parenting. It comprises four main scales all consisting of subscales. In this study, we only use main scale A, which consists of eight subscales (5-point Likert scale):  a) Acceptation (4 items), b) Able to manage (8 items), c) Experience problems (7 items), d) Want to change situation (6 items), e) Child is a burden (7 items), f) Being in it alone (4 items), g) Having fun (5 items), and h) Good interaction (5 items). All subscales are added up, converted into standard scores, and compared with average scores of the norm groups.
Behavior Rating Inventory of Executive Functions (BRIEF)	A norm-referenced parent-report measure of the child's executive function. It contains 75 items (score 'never', 'sometimes', 'often') in eight nonoverlapping clinical scales and two validity scales. These theoretically and statistically derived clinical scales form two indexes, both consisting of subscales:  a) Behavioral Regulation Index: Inhibit (10 items), Shift (8 items), and Emotional Control (10 items); b) Metacognition Index: Initiate (8 items), Working Memory (10 items), Plan/Organize (12 items), Organization of Materials (6 items), and Monitor (8 items). All scores form the Global Executive Composite, which takes into account all of the clinical scales and represents the child's overall executive function. The two validity scales (Negativity and Inconsistency) are used to determine if parental scores can be reliably calculated. The negativity scale is calculated by adding up the answers with a maximum score in this specific scale. The inconsistency scale is calculated by adding up 10 so-called 'different scores' between two items.
Child Behavior Checklist (CBCL)	A parent report questionnaire of 118 items to rate a child on various behavioral and emotional problems from 0 (absent) to 2 (often). It is made up of two higher order factors: internalizing and externalizing:  a) Internalizing Problem Scale; b) Externalizing Problem Scale.

### 3. Results

A total of 31 children met the inclusion criteria (Table 2). Five of these children had a confirmed ADHD diagnosis.

#### 3.1. Nijmegense Vragenlijst voor de Opvoedingssituatie

Mean NVOS scores were calculated for our group and compared with a healthy control group. Table 3 shows that overall parents of children with FLE did not express more-than-average parental burden.

Table 3 also indicates that parents of children who have had epilepsy for 5 years or longer reported more problems on the NVOS subscales 'Able to manage', 'Child is a burden', and 'Good Interaction' compared with the healthy controls. Parents of children who have had epilepsy shorter than 5 years expressed average scores.

**Table 2**  
Demographic and epilepsy variables.

Characteristics	Value
N	31
Patients	
– Gender (male:female)	18:13
– Mean age ( $\pm$ SD) in years at assessment	9.2 ( $\pm$ 1.6)
– Range (years)	7–12
Duration of epilepsy	
– Mean duration ( $\pm$ SD) in years	4.5 ( $\pm$ 2.7)
– Range (years)	1–9
– Short duration (< 5 years)	18 (58%)
Seizure focus based on EEG	
– Left frontal	10 (32%)
– Right frontal	6 (19%)
– Bifrontal	11 (34%)
– Frontal, but unknown lateralization	4 (13%)
Antiepileptic drugs	
– Monotherapy	12
– Polytherapy	16
– None	3

The correlations of the subscales of the NVOS with all subscales of the behavioral questionnaires are shown in Table 4. Correlations between almost all NVOS scales and the externalizing scale of the CBCL are high. There are no correlations between all NVOS scales and the MC of the BRIEF. Correlations between the NVOS scales and the BRI index of the BRIEF are small to high.

Because our sample size is small and internal correlations of about a third of the subscales of the NVOS are high ( $r_s \geq 0.70$ ,  $p \leq .000$ ), we only used subscale 'Child is a burden' of the NVOS for the regression analysis (Table 5). 'Child is a burden' significantly predicts scores on the Internalizing (20%) and Externalizing (37%) scales of the CBCL, the GEC (25%), BRI (49%), and negativity score (24%) of the BRIEF. It also explains a significant proportion of variance in those scores.

#### 3.2. Child Behavior Checklist and Behavioral Rating Inventory of Executive Function

Overall, parents reported significantly elevated problems in about 12% to 34% of the sample on all behavioral scales. Only 6% of the parents scored in the clinical range of the negativity scale of the BRIEF. For the inconsistency scale, the percentage of parents who scored in the clinical range was 45% (Fig. 2). Parents of children with epilepsy more than 5 years did not report significantly more behavioral problems on all different behavior scales compared with parents of children with epilepsy shorter than 5 years (lowest  $p > .07$ ).

Multiple regressions were run 1) to predict 'Child is a burden' based on 'outgoing behavior' and 2) to predict 'Child is a burden' based on 'introvert behavior'. A significant equation was found for 'outgoing behavior' ( $F(2,28) = 17.21$ ,  $p = .00$ ), with an  $R^2 = 0.55$ . The BRI of the BRIEF significantly predicted scores on 'Child is a burden' ( $b = 0.53$ ,  $t(28) = 3.34$ ,  $p = .00$ ). The Externalizing Scale did not add significantly to 'Child is a burden' ( $b = 0.30$ ,  $t(28) = 1.88$ ,  $p = .07$ ).

For 'introvert behavior', a small significant equation was found ( $F(2,28) = 3.88$ ,  $p = .03$ ) with an  $R^2 = 0.22$ . The Internalizing Scale significantly predicted scores on 'Child is a burden' ( $b = 0.44$ ,  $t(28) = 2.63$ ,  $p = .01$ ). The MC of the BRIEF did not add significantly to 'Child is a burden' ( $b = 0.15$ ,  $t(28) = 0.88$ ,  $p = .38$ ).

### 4. Discussion

We assessed the burden of parents of children with FLE. Overall, parents did not report more burden in comparison with the normative reference sample. However, parents of children with enduring epilepsy for more than 5 years did report more burden. These parents also experienced more problems in parenting, had difficulty to manage the problems, and interaction between parent and child was experienced as

**Table 3**  
NVOS scores in relation to healthy controls.

Scale	Healthy control group		Total group with FLE			Duration epi > 5 years			Duration epi < 5 years		
	M HC	SD HC	M FLE	SD FLE	d	M FLE > 5	SD FLE > 5	d	M FLE < 5	SD FLE < 5	d
Acceptation	1.40	0.49	1.41	0.59	0.02	1.39	0.53	−0.02	1.41	0.65	−0.02
Able to manage	1.71	0.56	1.81	0.62	0.17	1.91	0.70	0.32	1.74	0.57	−0.05
Experience problems	1.94	0.60	2.04	0.65	0.16	2.09	0.56	0.26	2.00	0.72	−0.09
Want to change situation	1.71	0.60	1.66	0.69	−0.07	1.83	0.74	0.18	1.54	0.65	0.27
Child is a burden	2.01	0.70	2.30	0.89	0.36	2.45	0.85	0.66	2.20	0.93	−0.23
Being in it alone	1.88	0.75	1.76	0.75	−0.16	1.82	0.69	−0.08	1.71	0.81	0.22
Having fun	1.57	0.53	1.46	0.53	−0.21	1.68	0.53	0.04	1.37	0.52	0.38
Good interaction	1.76	0.65	1.85	0.62	0.14	2.00	0.66	0.36	1.73	0.59	0.05

*d* = Cohen's *d*.  
HC = healthy controls.  
FLE = patients with frontal lobe epilepsy.

inadequate. These results might implicate that duration of epilepsy could be a risk factor for experiencing more burden in parenting. In this specific group with enduring epilepsy, the intractability of the epilepsy [1] and nocturnal seizures (and partly also poor quality of sleep), over a longer period of time may impact the family system [59,60] leading to exhausted parents. This can account for, at least a part of, the experienced burden. Surprisingly, the parents of children with enduring epilepsy did not report more behavioral problems compared with parents of children with a shorter duration in this study. This is surprising because it might be expected that these parents would report more behavioral problems [61–63]. In general, the demands on executive function, a frontal role, increases with brain maturation [64]. In FLE, especially, structural and functional disorders as well as epileptic discharges, interfering with physiological brain circuitry, may lead to executive dysfunction emerging over time [38,65] resulting in long-term developmental “lagging behind” [38,66,67]. These cognitive delay and comorbid (behavioral) problems are known to place a burden on parents in general (e.g., [21,22,68]), but in our small sample, it does not lead to more reported behavioral problems.

Our analyses suggest that self-reported parental burden is linked to reported outgoing/externalizing behavior especially, which concurs with other reports [45,46]. The findings are valid as far as the BRIEF negativity scale is concerned: responses of only 6% of the parents were unusually negative. However, almost 50% of the parents tended to be inconsistent in their ratings. Consequently, parents' reports should be cautiously interpreted. It should be noted that these validity scales pertain to the BRIEF only. This type of problem with validity in proxy measures is the so-called response inconsistency and can be caused by multiple factors (e.g., [69,70]). The inconsistency in our parents group

might be explained by the fact that children with epilepsy show huge variation in their behavior and cognitive skills, causing behavior difficult to rate. Furthermore, parents do not compare their children to healthy children but rate their children according to the circumstances. The latter meaning that parents might find that children are doing well at least in some situations despite their epilepsy. This could also explain the somewhat unexpected relatively low scores on the behavioral questionnaires, especially in the group with enduring epilepsy. All in all, inconsistency of parent ratings addresses an important issue, which is in need for further research.

It could be argued that there is a bidirectional effect between parental burden and behavioral problems in children with FLE, as it is common for epilepsy in general [8–12]. There were significant correlations between the behavioral scales and the experienced burden. These were high for more outgoing behavior, a feature more pronounced in children with FLE [38,39]. Moreover, experiencing that the child is a burden seems to predict behavioral scores (especially more outgoing behavior) and vice versa. These findings could strengthen the hypothesis that there is a bidirectional effect between parental burden and perceived behavioral problems. Further research in this area is needed.

There are a number of limitations in this study that has to be acknowledged. Our study is firstly limited by a relatively small sample size and the lack of a control group. The study explores a specific group, FLE, but there is still heterogeneity of the sample with respect to seizure type and underlying pathology. As this study is part of a larger study in which children were referred for test assessment, children with health or psychiatric problems, which could influence test assessment, were excluded. Consequently, parents of children with many behavioral issues may not have completed the questionnaires. Therefore, it could be argued that the current sample is not fully representative for children with FLE. However, it should be noted that a part of our sample did not have a psychiatric diagnosis but would meet the criteria for one. These children were not seen by a psychiatrist and were not given any diagnosis, because a part of the behavior was linked to their frontal disturbances. For future research, this needs to be taken into consideration.

**Table 4**  
Correlating NVOS with behavioral scales.

Behavior scales	Int	Ext	Total	BRI	MC	NEG	INC
Subscale NVOS	CBCL	CBCL	BRIEF	BRIEF	BRIEF	BRIEF	BRIEF
Acceptation	0.11	0.26	0.18	0.26	0.05	0.16	0.12
Able to manage	0.38*	0.72***	0.35	0.35	0.05	0.17	0.05
Experience problems	0.18	0.56***	0.36*	0.37*	0.09	0.22	0.09
Want to change situation	0.41*	0.71***	0.42*	0.57***	0.02	0.30	0.14
Child is a burden	0.43*	0.66***	0.60***	0.70***	0.19	0.51**	0.16
Being in it alone	0.30	0.41*	0.22	0.40*	0.06	0.26	0.08
Having fun	0.39*	0.54***	0.41*	0.37*	0.07	0.32	0.14
Good interaction	0.43*	0.63***	0.22	0.26	0.06	0.24	0.14

Correlation displayed as Spearman's  $r_s$ .  
Int = internalizing, Ext = externalizing, MC = Metacognition Index, NEG = negativity scale, INC = inconsistency scale.

\*  $p < .05$ .  
\*\*  $p < .01$ .  
\*\*\*  $p < .001$ .

**Table 5**  
Univariable regression.

Subscale	R <sup>2</sup>	F (1,29)	<i>p</i>	<i>t</i> (29)	$\beta$
Int CBCL	0.20	7.04	0.01	2.65	0.44
Ext CBCL	0.37	17.24	0.00	4.15	0.61
GEC	0.25	9.70	0.00	3.11	0.50
BRI	0.49	27.54	0.00	5.25	0.70
MC	0.03	0.94	0.34	0.97	3.56
Inc	0.02	0.65	0.43	0.81	0.27
Neg	0.24	10.23	0.00	3.20	0.51

Int = internalizing, Ext = externalizing, GEC = Global Executive Composite, BRI = Behavioral Regulation Index, MC = Metacognition Index, Inc = inconsistency scale, Neg = negativity scale.

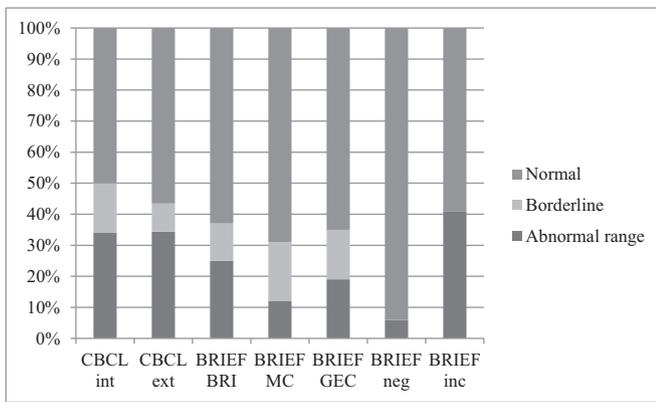


Fig. 2. Results of behavioral questionnaires.

Secondly, the NVOS is rarely used in clinical groups, and ecological validity may be questioned. Despite this, the high correlations of the NVOS with the CBCL and the BRIEF make it worthwhile to consider it more often for clinical use. The present study suggests a link between behavioral problems and caregivers' burden, as is suggested for epilepsy in general. This subject has not been investigated in this population systematically. The NVOS could potentially be a good questionnaire to measure this.

Lastly, we used the negativity scale and the inconsistency scale of the BRIEF to interpret ratings of other questionnaires. They are designed for the BRIEF; the generalizability to other ratings has not been investigated yet. Therefore, at this moment, scores on these scales can only be used to examine a possible tendency of negativism or inconsistency.

In clinical practice, the use of questionnaires related to parental burden and stress is advisable, since there seems to be a bidirectional relationship between behavioral problems and the burden as experienced by parents in children with epilepsy. Interventions based on this burden can also have substantial implications; treating and/or educating parents might diminish behavioral problems as well as the experienced burden. In addition, longer duration of epilepsy is considered a risk factor for developing psychopathology [8,23]. Hence, early intervention might help reduce psychopathology in children with FLE in the long term [71]. As the validity of parental reports can be questioned, other ways of obtaining information about a child's behavior and interaction with parents are encouraged. Developing a validity tool, such as The Structured Inventory of Malingered Symptomatology (SIMS; [72]), for parent-proxy measures is recommended. An issue that remains unknown at this time is the relation between parental burden and epilepsy (variables) itself. In general, the impact of epilepsy variables is not as clear as one might expect, as strong relationships between these variables and behavior are missing [41,73,74]. In future studies, it is worthwhile to explore these issues.

In sum, these findings suggest that parents of children with enduring FLE experience more parental burden. Furthermore, there seems to be an association between parental burden and behavioral problems in children with FLE, with more outgoing behavioral problems being the most pronounced. The inconsistency of the proxy reports is high and could make parental report less reliable.

## Declaration of Competing Interest

The author(s) declare(s) that there is no conflict of interest.

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