

Influence of parental stress in children with epilepsy

Influência do estresse dos pais nas crianças com epilepsia

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ABSTRACT

Objective: because treatment is aimed on seizure control, the stress produced by the disease is often neglected. The objective of this study was to evaluate the impact of epilepsy related stress on family and children with epilepsy. **Methodology:** this study was performed at the Pediatric Epilepsy Clinic of Outpatient Clinic of Neurology HC-Unicamp. We used the following instruments: Inventário de Sintomas de Stress para Adultos (ISSL) and Escala de Stress Infantil (ESI). **Result:** thirty consecutive patients were evaluated. Children stress was proportionally related to parental stress. Age of epilepsy onset, duration of epilepsy and seizure control did not influence the occurrence of stress. **Conclusion:** Epilepsy related stress is very frequent in children with epilepsy and usually is proportional to parental stress.

Keywords: stress, epilepsy, childhood

RESUMO

Objetivo: como o controle das crises epiléticas está no foco do tratamento da epilepsia, o estresse produzido pela doença é quase sempre negligenciado. Nesse sentido, o objetivo deste estudo foi avaliar o impacto da epilepsia relacionado ao estresse na família e nas crianças com epilepsia. **Metodologia:** o presente estudo foi desenvolvido na Clínica de Epilepsia Pediátrica do Ambulatório de Neurologia do Hospital de Clínicas da Unicamp, a partir dos seguintes instrumentos: Inventário de Sintomas de Stress para Adultos (ISSL) e Escala de Stress Infantil (ESI). **Resultado:** foram analisados 30 pacientes. Crianças com estresse estiveram proporcionalmente relacionadas ao estresse parental. A idade de início da epilepsia, a duração da epilepsia e o controle das crises não influenciaram a ocorrência de estresse. **Conclusão:** a epilepsia associada ao estresse é bastante frequente em crianças com epilepsia, e geralmente é proporcional ao estresse parental.

Palavras-chave: estresse, epilepsia, infância

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INTRODUCTION

It is known that epilepsy has a negative effect in the quality of life of patients and family members^{1,2,3,4,5,6,7}. Although most studies regard adults with epilepsy, the impact of the disease in the quality of life of children with epilepsy has also been shown by several studies^{8,9,10,11}.

Misinformation and negative perception of epilepsy in our society contributes to the stress presented by young patients with epilepsy and their parents¹². Discrimination and psychosocial difficulties can be more stressful and harmful than seizures themselves^{13,14,15}.

The impact of parental stress on children with epilepsy is not well established yet. The objective of this study was to evaluate the impact of parental stress on children with epilepsy.

METHODS

This study was performed at the Pediatric Epilepsy Clinic of our University Hospital, from August 2011 to March 2012.

Inclusion criteria was: a) age between 6 and 14 years-old; b) diagnosis of epilepsy, c) normal neurological examination; d) signature of informed consent by parent or legal guardian. Exclusion criteria was: a) age younger than 6 or older than 14 years-old; b) diagnosis of epilepsy due to a progressive disorder, such as brain tumor or metabolic disease; c) abnormal neurological examination; d) developmental delay; e) absence of informed consent signed by parent or legal guardian.

Information about type of epileptic syndrome, seizure frequency, neuroimaging findings and type of antiepileptic drugs used was collected from clinical files. Patients and families were interviewed by one of the authors (ACP) following two structured

questionnaires: *Inventário de Sintomas de Stress para Adultos*¹⁶ and *Escala de Stress Infantil*¹⁷. This study was approved by the IRB of our institution. Statistical analysis was performed using the Fisher Exact Test and Student t-test, with a level of significance of 0.05.

RESULTS

Thirty consecutive patients that met the inclusion criteria were evaluated. There were 20 boys and 10 girls, ages ranging from 7 to 14 years-old (mean = 11.4 years). The type of epileptic syndrome was focal in 23 patients and generalized in six patients. The type of epileptic syndrome could not be established in one patient. Neurological examination was normal in all patients.

Seizures started from age one month to 11 years-old (mean = 4.5 years). Epilepsy duration ranged from 1 to 12 years (mean = 6.8 years). Twenty-one patients were seizure free for at least three months (Table 1).

Twenty-one patients were on monotherapy and nine patients were on polytherapy. Antiepileptic drugs used were: carbamazepine in 15, valproic acid in eight, phenytoin in three, clobazam in three, lamotrigine in three, phenobarbital in two, clonazepam in two, and topiramate, gabapentin, oxcarbazepine and levetiracetam in one each.

Twenty-five (83.5%) parents and 23 (76.5%) patients had symptoms of stress. Seizure control did not influence parental (Table 2; $p=1$) or patient stress (Table 3, $p=0.6402$). Age of epilepsy onset or duration of epilepsy did not influence either parental or patient stress (Table 4).

The only predictor for patient stress was their parent's attitude toward the disease; therefore, patient stress was proportional to parental stress (Figure 1).

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TABLE 1 – Distribution of stress according to duration of epilepsy, age of epilepsy onset, and seizure control.

Patient ID	Child Stress	Parental Stress	Duration of Epilepsy (years)	Age of Epilepsy Onset	Seizure Control (>3 months)
1	YES	YES	8	3	YES
2	YES	YES	8	1	YES
3	YES	YES	9	1	YES
4	YES	NO	11	2	YES
5	YES	YES	11	0.5	NO
6	YES	YES	6	3	NO
7	YES	YES	3	8	YES
8	YES	YES	5	7	NO
9	NO	YES	9	3	NO
10	YES	YES	10	3	YES
11	YES	YES	6	8	YES
12	YES	YES	1	6	NO
13	YES	YES	3	9	YES
14	NO	NO	2	10	NO
15	NO	YES	6	7	NO
16	YES	YES	2	11	NO
17	NO	NO	2	10	YES
18	NO	NO	10	4	YES
19	NO	NO	12	1	YES
20	YES	YES	10	2	YES
21	YES	YES	8	6	YES
22	YES	YES	2	5	YES
23	YES	YES	5	2	YES
24	YES	YES	3	6	YES
25	YES	YES	10	1	YES
26	YES	YES	6	8	NO
27	YES	YES	6	4	YES
28	YES	YES	7	0	YES
29	NO	YES	11	3	YES
30	YES	YES	12	1	YES

Table 2 – Influence of seizure control on parental stress (p=1).

	Seizure free patient	Seizures not controlled by AED
Positive Parental Stress	17	8
No parental stress	4	1

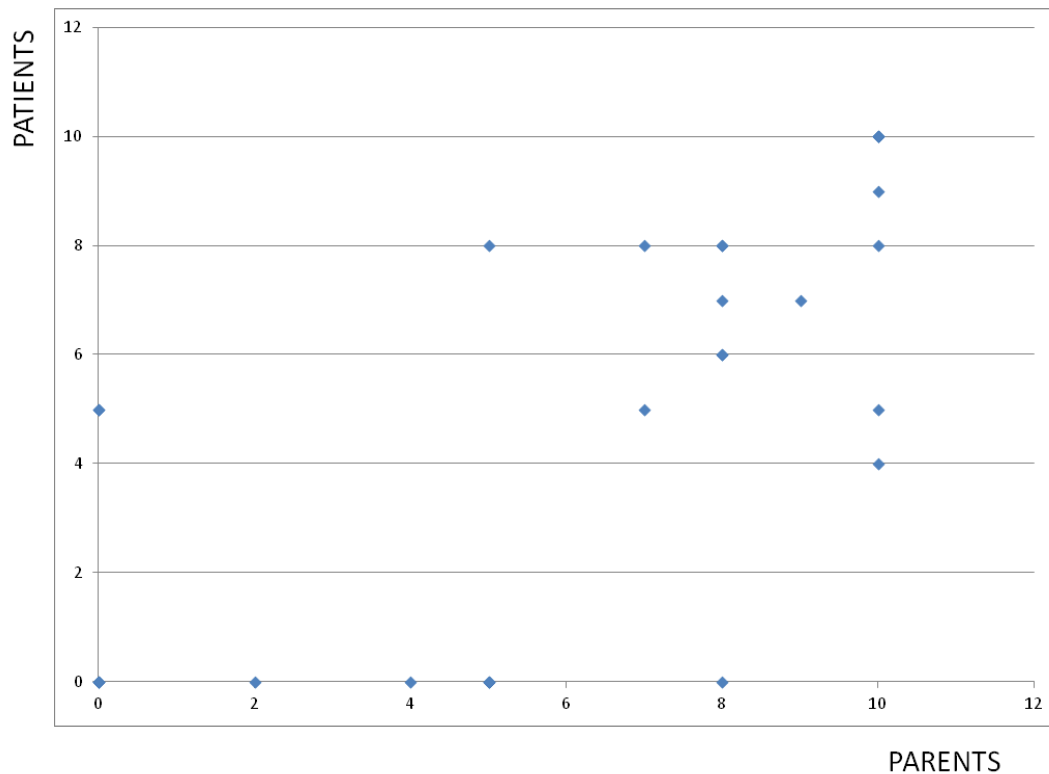
Table 3 – Influence of seizure control on patient stress (p=0.6402).

	Seizure free patient	Seizures not controlled by AED
Positive Patient Stress	17	6
No Patient Stress	4	3

Table 4 – Influence of age of epilepsy onset and epilepsy duration on parental stress.

Epilepsy Related Stress	Variable	Stats
Positive Parental Stress	Age of Epilepsy Onset = 0 to 11; mean = 4.3 years	p=0.5158
No Parental Stress	Age of Epilepsy Onset = 1 to 10 years; mean = 5.4 years	
Positive Parental Stress	Duration of epilepsy = 1 to 12 years; mean = 6.6 years	p=0.5885
No Parental Stress	Duration of epilepsy = 2 to 12 years; mean = 7.4 years	
Positive Patient Stress	Age of Epilepsy Onset = 0 to 11; mean = 4.2 years	p=0.4068
No Patient Stress	Age of Epilepsy Onset = 1 to 10 years; mean = 5.4 years	
Positive Patient Stress	Duration of epilepsy = 1 to 12 years; mean = 6.6 years	p=0.6758
No Patient Stress	Duration of epilepsy = 2 to 12 years; mean = 7.4 years	

Figure 1 – Correlation of parents stress level and patient stress.



DISCUSSION

The treatment of epilepsy is focused on seizure control; and most children become seizure free after the introduction of one antiepileptic drug. Therefore, even experienced epileptologists often neglect the influence of seizure related stress in the lives of patients and their families^{5,9,10}.

Seizures are one of the most frightening event a parent can experience. In addition, epilepsy demands prolonged antiepileptic drug treatment. Therefore, sometimes, the family cannot cope with the diagnosis of epilepsy, even when the child is seizure free for a long period of time. Most often, parental stress is really high.

Our data shows that most parents (83.5%) their children (76.5%) had symptoms of stress. Children have a negative perception about epilepsy. This perception probably reflects the society's collective unconscious prejudice toward epilepsy and people with epilepsy^{12,13}. In addition to the children negative perception of epilepsy, parental stress can harm their child more than the seizures themselves. Our data showed that patient stress was proportional to parental stress.

It is important to note that seizure freedom did not correlate with better stress outcome. However, the presence of stress may be related to an increase in seizure frequency, with a median increase of 2.5 times the frequency compared to nonstressful periods¹⁸. Another interesting finding was that age of epilepsy onset or duration of epilepsy also did not impact the stress occurrence.

We conclude that epilepsy related parental stress is very frequent and should be targeted as an important part of the treatment of epilepsy in childhood, because it is directly related to the stress presented by young patients.

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