

Parental Stress in New-Onset Epilepsy and After Therapy Withdrawal

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Abstract: *Objective: To assess maternal and paternal stress in parents of children with epilepsy, at the time of diagnosis, after one year of follow-up and after therapy withdrawal.*

Methods: We investigated parental stress in a sample of 85 children aged 2-14 years, divided into two groups based on the diagnosis: Group 1 (50 patients) with Childhood Absence Epilepsy or Idiopathic Focal Epilepsy with Rolandic discharges; Group 2 (35 patients) with different forms of drug-resistant Epilepsy. Every parent completed the Parental Stress Index-Short Form at Time 0, when they received the diagnosis and patients started therapy, at Time 1, after 1 year of follow-up. Only parents of Group 1 completed the same questionnaire after 2 years therapy withdrawal.

Results: We found high levels of stress in both mothers and fathers at Time 0, without statistically significant differences between the two groups. At Time 1, stress values were unchanged in Group 1 mothers; conversely, the levels of stress in Group 1 fathers were reduced, with average values that fell within the "normal range". In group 2, stress levels were reduced both in mothers and fathers at Time 1, compared to Time 0, but equally fell into the "clinical range", for both parents. In Group 1, even one and two years after therapy withdrawal, parental stress did not normalize and all scores persisted in the "clinical range" in both mothers and fathers.

Conclusions: Our study revealed that, the diagnosis of epilepsy itself tended to increase parental stress, apparently regardless of the severity of the disorder; even after a period of follow-up, when epilepsy was better controlled, overall parental stress remained high. Parental stress levels remained higher than expected, even 2 years after the suspension of therapy and the absence of seizures. This was probably due to concerns with the reappearance of new seizures or a more severe type of epilepsy with the suspension of drug(s), and feelings of inadequacy with their parental role(s).

Keywords: *children; epilepsy; parental stress.*

How to cite: Operto, F.F., Pastorino, G.M.G., Coppola, G. (2020). Parental Stress in New-Onset Epilepsy and After Therapy Withdrawal. *BRAIN. Broad Research in Artificial Intelligence and Neuroscience*, 11(1Sup2), 44-50.
<https://doi.org/10.18662/brain/11.1Sup2/37>

Introduction

Several recent studies showed that Parental Stress level is higher in the parents of children with severe chronic conditions than in the general population (Lyons et al 2010, Patton et al 2011, Streisand et al 2005, Powers et al 2002, Chiou & Hsieh 2008, Reichman et al 2008, Farrace et al 2013, Rodenburg et al 2007, Britner 2003). Epilepsy, with a prevalence of about 1%, is one of the most common neurological pathologies in childhood and the parents of children with epilepsy can also show high levels of Parental Stress (Cowan 2002, Wirrell et al 2008, Rodenburg et al 2005). There are many factors that can contribute to increasing parental stress and dysfunctional family relationships, such as a new diagnosis of epilepsy, the fear of seizures recurrence and of drugs adverse effects, the seizure effect on the development of cognitive functions (Shore et al 2002, Chapieski et al 2004, Modi 2009, Dumbrava et al 2019). Parental stress can be particularly high in drug-resistant epilepsy, a condition that occurs in 20-30% of cases (Wirrell et al 2008). Psychiatric comorbidities, such as behavioral and mood disorders in children with epilepsy, can often also aggravate the stress of parents, who report an impairment of their social life and sleep disturbances. Symptoms can evolve to suicide or para-suicide (Fulga et al 2008). Sometimes it is necessary a psychiatric expertise (Dumbrava et al 2013).

The purpose of our study is to evaluate stress levels in parents of children with different forms of epilepsy over time.

Methodology

Participants

Our study involves 85 children diagnosed with epilepsy (mean age = 9.2 ± 2.6 years) and their parents, recruited from the Child Neuropsychiatry Unit of the University of Salerno (Italy).

We considered a group of children with different forms of drug-resistant epilepsy ($n=35$) and a group of children with non drug-resistant epilepsy ($n=50$).

All parents, both mother and father, underwent parental stress assessment through a standardized neuropsychological questionnaire, the Parental Stress Index-Short Form (PSI-SF). PSI-SF was performed at the time of diagnosis and after 12 months (Time0 and Time1). In the group of controlled patients it was repeated even 12 months and 24 months after the suspension of therapy (Time2 and Time 3).

The parents were fully and clearly explained about the aims and methods of our study and provided their informed consent.

The study was conducted according to good clinical practice, in compliance with the ethical principles of the Helsinki Declaration.

Parenting Stress Index – Short Form

PSI-SF is a self-administration questionnaire for parents which measures the following scales:

- Parental Distress (PD): stress related to the mother/father role
- Dysfunctional parent-child interaction (P-CDI): stress associated with conflicting parent-child relationships
- Difficult Child (DC): stress associated with the characteristics of child
- Total Stress (TS): global stress level

The scores <85 is normal, instead higher than 85 rank in "clinical range".

Results

At baseline all parents, regardless of type of epilepsy (drug resistant or non-drug resistant) and other factors (e.g. number of seizures), had stress levels increased on three PSI scales (PD, P-CDI and TS).

After 12 months, in the non-drug resistant group, the mothers' stress scores were still the same, (pathological score) while the fathers' stress scores had decreased (normal score) with a statistically significant difference ($p < 0.05$).

In the drug-resistant group the levels decreased in both parents ($p < 0.05$) but were still in the pathological range. (Figure 1)

In the non-drug resistant group, after 12 months and 24 months of antiepileptic therapy withdrawal, stress levels were not significantly reduced compared to baseline in both parents ($p > 0.05$) (Figure 2). Stress levels between mother and father were significantly correlated ($p < 0.05$)

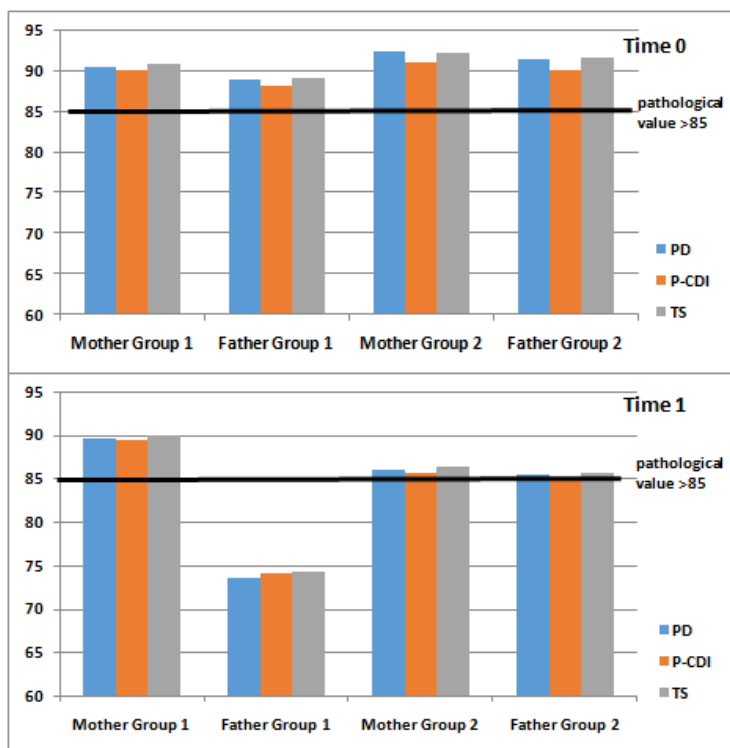


Fig.1: Mean stress scores in mothers and fathers at Time0 and at Time1.

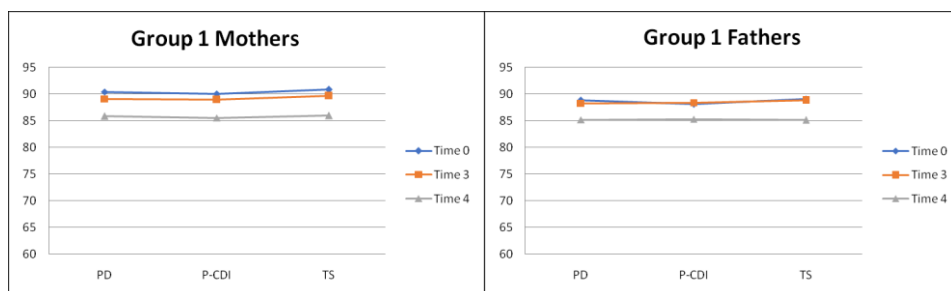


Fig. 2: Mean stress scores in mothers and fathers at Time0, Time3 and Time 4.

Conclusions

In keeping with other literature data, our study revealed that Parental Stress level of parents of children with epilepsy were high (Reichman et al 2008, Rodenburg et al 2007, Britner et al 2003). In our study, the increase in parental stress is not linked to the characteristics of the disease (e.g. number

of seizures, monotherapy/politherapy). Contrary to what has been reported by some previous studies, in our study the stress levels seem more related to the parent's role in managing the child than to the characteristics of the child himself (Wirrell et al 2008, Abidin 1995, Shatla et al 2011).

After 12 months in the non-drug resistant group, the stress levels of mothers are still high while those of fathers normalized (Figure 1). This could mean that, while fathers are more easily reassured about the child's clinical condition, mothers are still concerned about child management, seizure recurrence and the side effects of therapy. This data is in agreement with the previous literature which reports high levels of stress in mothers of children with refractory epilepsy (Wirrell et al 2008).

In the non-drug-resistant group, after 12 and 24 months from therapy withdrawal, parental stress levels are unexpectedly still high, and do not normalize neither in fathers nor in mothers.

Some literature studies showed a reduction of parental stress after epilepsy surgery or vagus nerve stimulation, however there aren't currently studies on parental stress after therapy withdrawal (Braams et al 2015, Li et al 2007, Fan et al 2018).

In conclusion our study revealed that epilepsy in children involves high parental stress levels, regardless of some characteristics of epilepsy itself (such as seizure number, seizure type or number of antiepileptic drug assumed). Our study also shows that parental stress remains high, despite the control of symptoms or the suspension of drug therapy. Parents are probably always worried about seizure recurrence, therefore more support is needed for parents in managing children with epilepsy.

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