# Correlates of parental stress and psychopathology in pediatric epilepsy

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## Abstract

**Background:** Chronic conditions like epilepsy in a child can affect his/her entire family. The failure of the family members to adapt adequately to the unique demands of this childhood chronic illness can be considered as an important risk factor for development of psychopathology. **Objectives:** The objectives of this study were to study the profile of parenting stress in parents of children with epilepsy and its correlates; and, to examine the correlates of psychopathology in these children. **Material and Methods:** Twenty three epileptic children and their families were subjected to Parenting Stress Index (PSI), Scores for indices such as The Children's Depression Inventory (CDI), Benton Visual Retention test, Spence anxiety scale for children, The Child Behavior Checklist (CBCL) and Wechsler Intelligence Scale for Children were calculated. **Results:** Mean verbal and performance IQ score was 94, while the mean total IQ score was 95. Mean scores for all Wechsler IQ Scores as well as Benton Visual retention test were within the average range. Means for total internalizing CBCL t scores (M, Mean=70; Standard Deviation, SD=4.4), total externalizing CBCL *t* scores (M=60, SD=9.6), and total behavior problems CBCL t scores (M=67, SD=5.2) were above the standard cut off levels of 65 for clinical behavioral problems. Mean score on CDI was 42 ± 2. Scores of the PSI equal to or higher than 85$^{th}$ percentile were considered pathologically high. **Conclusion:** The results of our study indicated that pediatric patients with epilepsy, specifically with intractable cases, are correlated with high levels of parental stress.

## Key Words

Epilepsy, parental stress, pediatric, psychopathology

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## Introduction

Pediatric epilepsy is the most common chronic neurological illness in childhood and adolescence.[1] Fifty million people worldwide have epilepsy, of whom 33 million are children. Being a chronic and challenging physical illness for children and their families, a thorough understanding of the biopsychosocial concerns in pediatric epilepsy can enable medical providers and mental health clinicians to promote resiliency and adaptation in children and their families facing troubling seizure disorders.[2] Childhood chronic conditions like epilepsy are considered to affect the whole family, requiring new modes of organization and structure for the family. The failure of the family members to adapt adequately to the unique demands of this chronic childhood illness could therefore, be considered a risk factor for development of psychopathology.[3,4] Psychopathology refers to psychological stresses and behavioral disturbances that occur in children.

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Psychopathology in children with epilepsy should not be attributed solely to the chronicity of the disease, but to specific epilepsy-related factors, including the underlying brain dysfunction. This is in line with the general finding that children with neurological disorders are at higher risk for psychopathology than children with non-neurological diseases.[5] The development or maintenance of psychopathology in children with epilepsy may also be influenced by family factors, such as increased parenting stress.[3]

Family factors, especially those related to the quality of the parent-child relationship (such as parental rejection), have been found to exert negative effects on child development; and thus, are considered to be important risk factors for the development of child psychopathology.[6]

### Hypothesis

It was hypothesized that parents of children with epilepsy would have higher levels of parenting stress, including both generic and epilepsy-specific stress. Also, children with epilepsy

would have significantly high rate of psychopathology, which is influenced by the level of parental stress as well as by the epilepsy variables.

### Aim of the work

- The main aim of the current study was to study the profile of parenting stress in parents of children with epilepsy and its correlates.
- The second aim was to examine the correlates of psychopathology in these children.

## Material and Methods

Potential participants were approached and recruited from a pediatric epilepsy clinic if they met the following inclusion criteria: a) children 9-12 years old, b) diagnosis of epilepsy requiring treatment c) no co-morbid medical conditions requiring daily medications, and d) no significant developmental delays (e.g., Autism, Mental retardation, MR). As a part of routine clinic care, patients were scheduled to return to the clinic one month after diagnosis and every three months thereafter.

### Parenting Stress Index

The Parenting Stress Index (PSI)[7] is a 120-item parent self-report measure designed to assess the degree to which stress is related to parent functioning, the behavioral and temperamental qualities of the child, and the parent-child relationship. The PSI is comprised of 6 child domains (Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability) and 7 parent domains (Competence, Isolation, Attachment, Health, Role Restriction, Depression, Spouse). Individual subtest scores for each domain are calculated, as well as Child and Parent domain scores and a Total Score are obtained. Parents scoring above the 85$^{th}$ percentile for these scales were considered to be experiencing high levels of stress. Reliability coefficients for the Child and Parent domains and the Total Stress Scale were 0.90 or greater.[7] Child and Parent domain total scores, and Total Stress were used for the current analyses.

### The Children's Depression Inventory

This 27-item self-report instrument for 7- to 17-year-old children and adolescents has a 3-point scale and produces a total score (T score) and five factor scores. It has a solid internal consistency reliability (0.59-0.88), and variable test/retest reliability (0.38-0.87). It is sensitive to change, has good normative data, and has been extensively used in children with chronic illness and developmental disorders. The Children's Depression Inventory (CDI) T scores of ≥50 were considered clinically relevant.[8]

### Benton Visual Retention test Fifth Edition (Previous 1)

More than 50 years of proven clinical utility is the hallmark of *Benton Visual Retention test*®. This test has proven its sensitivity to reading disabilities, nonverbal learning disabilities, traumatic brain injury, Attention-Deficit Disorder, Assess visual perception, memory and visuo-constructive abilities.[9]

### Spence anxiety scale for children

Spence anxiety scale for children is a list of 17 items that describe children anxiety symptoms. For each item, the participate circles the response that best describes the child; three if the item is very often true, two if the item is quite often true, one if the item is sometimes true and 0 if the item is seldom true or if it is not true at all.[10]

### The Child Behavior Checklist

Psychopathology was measured with the The Child Behavior Checklist (CBCL), which is well known for its reliability and validity. Parents completed the 118 questions pertaining to behavior problems, which were scored on a 3-point scale ranging from "not true" to "often true" for the child.[11] Broad-band psychopathology includes Internalizing behavior problems and Externalizing behavior problems. Externalizing Problems (includes Delinquent and Aggressive Behaviors), Internalizing Problems (includes Withdrawn, Somatic Complaints, and Anxiety/Depressed Problems), and Total Problems (includes Externalizing, Internalizing, Social, Thought, and Attention Problems)[12] and cut-off scores of 65 (2 SD above normal level) have been recommended as clinically meaningful thresholds for a deviation from age- and sex-matched healthy children Scores that were above 67 are referred to as 'at-risk' for problems.

### The Wechsler Intelligence Scale for Children-Revised

Wechsler Intelligence Scale for Children - 4$^{th}$ edition (WISC-IV), Full Scale, Verbal, and Performance IQ scores were calculated.[13]

### Statistical analysis

Frequencies were generated for all categorical variables, and descriptive statistics were calculated for all continuous variables. To achieve the aim of the current paper, statistical analysis was divided into descriptive and analytic components. Mean scores, SD, *T* test as well as Pearson correlation test were used were needed.

## Results

The study group was composed of 23 cases; 10 with controlled epilepsy and 13 with intractable epilepsy. There were 8 females and 15 males with a mean age of 11.8 years. Among the study group, 15 cases had the diagnosis of generalized tonic clonic epilepsy and the rest had a diagnosis of focal epilepsy. The entire group studied was on polypharmacy. Mean verbal and performance IQ score was 94, while the mean total IQ score was 95. Mean scores for all Wechsler IQ Scores as well as Benton Visual retention tests were within the average range. Means for total internalizing CBCL *t* scores (*M*=70, *SD*=4.4), total externalizing CBCL *t* scores (*M*=60, *SD*=9.6), and total behavior problems CBCL *t* scores (*M*=67, *SD*=5.2) were above the standardized cutoff of 65 for clinical behavioral problems. Ten cases (43%) showed mean total CBCL equal to or more than 70, indicating high level of severity of behavior problems. Of those, 6 (60%) showed internalizing scores of 70 or more and 4 (40%) showed high externalizing scores (70 or more). The mean score on the CDI was 42 ± 2, yet 2 cases out of 23 (8%) were diagnosed as depression (scores >50 on CDI); while 3 cases (13%) scored positive for anxiety disorders**.** Scores of the Parenting Stress Index (PSI) equal to or higher than 85$^{th}$ percentile are considered pathologically high. Abnormal results on the scale of PSI were shown in Table 1.

### Correlation of Parenting Stress Index to demographic and disease variables

There was no correlation between composite PSI on one side and age or gender. There was a significant positive correlation between composite PSI total score and seizure severity, measured by Chalfont ($P$<0.05). The frequency of epileptic seizures was positively related to demandingness (0.01), and to maternal depression (0.02). The PSI was generally higher among patients with generalized seizures. In the current study, comparing intractable cases to controlled cases, Composite Parental stress index, child and parent domains were significantly higher among the intractable group. Demandingness and parental health were the highest among the intractable group (<0.01) as seen in Table 2.

### Correlation of Parenting Stress Index to cognitive tests

Comprehension subtest of Wechsler was negatively correlated to demandingness ($P$<0.05). Yet no other significant correlations with any other Wechsler subscales or with - Benton Visual retention test were noted. There was no correlation between composite PSI, parental domain of parental stress and children cognitive functions.

### Correlates of children psychopathology

Age was negatively correlated to aggression problems ($P$<0.05) and anxiety was positively correlated to demandingness (0.05). Externalizing problems were significantly higher among children with generalized tonic clonic fits, while there was a tendency towards higher levels of internalizing problems among children with focal fits, as shown in Table 3. Composite stress index and internalizing problems were significantly correlated. Whereas there was no significant relation with externalizing problems, there was a significant positive correlation between composite PSI on one side and child depression and anxiety on the other side ($P$<0.05). There was no relationship between studied neuropsychological tests and psychopathology. There was no statistically significant difference between the intractable group and the controlled group regarding rates of psychopathology as measured by CBCL. Internalizing problems were significantly correlated to seizure severity. Adaptability was significantly correlated to anxiety ($P$<0.05). Acceptability (this child is not the child that the parents had hoped) was positively correlated to externalizing problems.

## Discussion

Childhood epilepsy with its unpredictable episodes, long-term prognosis, and co-morbid behavioral problems is a continuing source of stress for the family.[14] The aim of the current study was to study the profile of parental stress and its correlates in children with epilepsy. As was hypothesized, high level of parental stress was observed in all three domains for the child and parent. The child domain" which assesses characteristics displayed by children that make them difficult to parent "was significantly higher compared to the parent domain. This is in line with the study of Wirrel *et al*.,[15] which showed that increased stress is predominantly due to child factors. According to the parental perception, the child domains, associated with the highest levels of stress were as follows:

**Table 1: Parental Stress Index in the study group (percentile of parent and child domain)**

| Total Parental Stress Index | 90th percentile |
|---|---|
| Child domain | |
| Reinforces parent (parent-child interaction fails to produce positive feelings) | 95th percentile |
| Acceptability (this child is not the child that the parents had hoped) | 85th percentile |
| Demandingness (child is placing unrealistic demands upon parent) | 90th percentile |
| Emotional instability | 90th percentile |
| Total stress child domain | 90th percentile |
| Parent domain | |
| Parental health (perception of physical health is deteriorating) | 85th percentile |
| Role restriction (freedom has been restricted by the child) | 90th percentile |
| Attachment (cold parent-child interactions) | 95th percentile |

Child domain of parental stress was significantly higher than the parental domain ($P$<0.05)

**Table 2: Comparing parents of children with intractable epilepsy to those with controlled epilepsy regarding Parenting Stress Index in the study**

| PSI subscale | Intractable seizures group (mean ± standard deviation) | Controlled seizures group (mean ± standard deviation) | *P* value |
|---|---|---|---|
| Composite PSI score | 333.9 ± 3.534 | 260 ± 140.231 | <0.001 |
| Child domain | 160.5 ± 43.4 | 122 ± 27 | <0.05 |
| Demandingness | 22.400 ± 10.015 | 7.000 ± 2.530 | <0.01 |
| Emotional instability | 19.667 ± 2.658 | 15.250 ± 2.062 | <0.05 |
| Child depression | 19.00 ± 5.514 | 11.250 ± 3.202 | <0.05 |
| Parent domain | 173 ± 44.4 | 138.7 ± 20.53 | <0.05 |
| Efficiency | 34.833 ± 7.140 | 24.750 ± 3.304 | <0.05 |
| Isolation | 19.33 ± 3.266 | 14.50 ± 1.000 | <0.05 |
| Parental health | 19.167 ± 3.656 | 12.750 ± 0.500 | <0.01 |

*$P$ value is significant<0.05, **$P$ value is highly significant<0.01, PSI = Parental stress index

**Table 3: The correlation between seizure pattern and child psychopathology as observed in the study**

| CBCL subscale | Type of seizure | | *t*-test | |
|---|---|---|---|---|
| | GTC (mean ± standard deviation) | FOCAL (mean ± standard deviation) | T | *P* value |
| Internalizing problems | 50 ± 1.364 | 70.0 ± 13.266 | −1.921 | 0.081 |
| Externalizing problems | 75 ± 3.354 | 35 ± 1.225 | 2.113 | 0.056 |

Insignificant $P$ value>0.05, CBCL = Child behavioral checklist; GTC = Generalized tonic clonic seizure; T = The test statistic

Parent-child interaction fails to produce positive feelings (reinforces parent); when this child is not the child that the parents had hoped (acceptability); and, when child is placing unrealistic demands upon parent (demandingness).The child's emotional instability was also among the main causes of parental stress.

Other factors in the parental domain and associated with high

levels of stress included that the physical health is deteriorating (parental health), the sense of freedom has been restricted by the child (role restriction), as well as cold parent-child interactions (attachment). Studies have shown that families of children with epilepsy report dissatisfaction with restriction in their social (e.g., eating out, entertainment) and recreational activities.[16] In a previous study done on intractable cases of epilepsy, mothers scored more adversely on the Isolation, Health, Role Restriction, and Spouse subscales of the Parent Domain, but more favorably on the Attachment subscale.[15] This study hypothesized that seizure variables might influence the level of parental stress and this was proved as parental stress was higher among children with generalized tonic clonic seizures compared to those with focal seizures. Comparing intractable to controlled cases, parental stress was significantly higher among intractable cases. This is in line with the study of Wirrel *et al*.,[15] that stated that intractable childhood epilepsy is associated with markedly increased maternal parenting stress. In fact, studies indicate that 45-65% of parents of children with intractable epilepsy experience elevated levels of parenting stress.[17] Demandingness and poor parental health were significantly higher among the intractable group followed by emotional instability, efficiency and role restriction.

There is indeed empirical evidence showing that children with epilepsy exhibit more psychopathology than children from the general population. For example, the epidemiological Isle of Wight studies revealed that 28.6% of the children with uncomplicated epilepsy had psychiatric disturbances compared with 6.6% of the children from the general population.[18] Another study showed that psychopathology occurs in 37% to 77% of children with epilepsy.[19] In the current study, the rate of psychopathology was 43%, which may be due to the presence of intractable cases among the study group. In general, children with epilepsy display more internalizing problems (withdrawal, somatic complaints, anxiety, and depression symptoms) than externalizing problems such as acting out and conduct problems.[20,21] In a recent meta-analysis, researchers found larger effect sizes for comparisons between children with epilepsy and normative controls as regards internalizing problems than externalizing problems.[22] This is in line with our study which showed higher mean scores for internalizing problems compared to externalizing problems.

A previous study showed psychopathology in 63% of children with partial seizures and 55% of the children with generalized seizures.[23] In the current study, the type of seizures seemed to influence the type of psychopathology as internalizing problems were more among cases with focal fits, while externalizing problems were significantly higher among generalized fits. This contradicts the study of Freilinger *et al*.,[24] which found no statistically significant associations between the CBCL scores and seizure symptoms, frequency and electroencephalography (EEG) findings at the time of evaluation. Some studies report no association with seizure variables. Other studies report an association with seizure frequency.[25]

In a prior study by Oguz *et al*.,[26] we found a trend for depression in older children with epilepsy and for anxiety in the younger children. Yet in the current study, age was the only negatively correlated factor with aggression and conduct problems with no other correlations to psychopathology. In the previous studies conducted with community or university-affiliated settings, depression and anxiety were found in 16% to 31% of children and adolescents with epilepsy.[27,28] In the current study, 8% were positive for depression on CDI. This is in line with the previous study that stated that approximately one child with epilepsy in 10 had evidence of a mood disorder.[29] Childhood depression was significantly higher among intractable cases. This wide range reflects methodological differences, such as differences in types of diagnostic instruments (e.g., structured psychiatric interviews, self-report scales), chronicity of study samples (new-onset seizures, chronic epilepsy, postsurgical patients), and sample size.[28]

Thirteen percent were positive for anxiety as measured by Spence anxiety scale for children. These findings support the contention that anxiety disorders are more frequent than mood disorders in persons with epilepsy.[29,30] Anxiety was significantly correlated to demandingness which is the parent's perception that the child is placing unrealistic demands upon him or her. In line with other research findings that high demandingness describe the child as being unreasonable, impatient, and needy.[7] In a 2-year follow-up of children with new onset seizures, both parents[31] and teachers[32] rated children with recurrent seizures to have a higher total and internalizing problem scores on the CBCL, than children with no additional seizures.

## Summary

Results of our study indicate that pediatric epilepsy, specifically with intractable cases, is correlated with high levels of parental stress. Children with epilepsy are at high risk for co-morbid internalizing and externalizing problems. Co-morbid psychopathology has a significant impact not only on the child, but also, on the parents and is a source of increased parental stress. Multidisciplinary management strategies would advance clinical practice in this highly complex field of pediatric neuropsychiatry. Assessments of depression and learning must be considered because of their potential impact on parenting stress and the child's overall quality of life (QOL). Increased awareness and early diagnosis may affect therapeutic intervention and long-term outcomes. To effectively manage children with epilepsy, assessments of psychopathology must be considered because of their potential impact on parenting stress and the child's overall QOL. The high prevalence of problems emphasizes the need for behavioral assessment and treatment as a part of any comprehensive epilepsy clinic. The use of a relatively uncomplicated and focused assessment for behavioral and emotional problems in the comprehensive epilepsy clinic has the potential to significantly improve the mental health care of children and adolescents with epilepsy. Future studies are needed to further examine factors such as social support and epilepsy-specific variables (e.g., type of epilepsy, number of seizures) on parenting stress and activity patterns in a larger cohort of children with epilepsy. Child behavior problems, family environment, and parenting behaviors should be assessed when children present to the clinical setting with new-onset seizures.

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