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Impact of pediatric epilepsy on Indian families: Influence of psychopathology and seizure related variables

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Abstract

The impact of epilepsy on families has been little studied in the developing countries, where it is the most common neurological disorder among children. In Vellore, India, the impact on 132 families who had a child with epilepsy was rated with the Impact of Pediatric Epilepsy on the Family Scale (IPES). An adverse impact was experienced by 42% of families. Multivariate statistical analysis revealed four factors that were significantly associated with high impact: fewer years since diagnosis (OR = 0.81, 95% CI = 0.71–0.93), fewer months since last seizure (OR = 0.58, 95% CI = 0.39–0.87), treatment with multiple antiepileptic drugs (OR = 4.34, 95% CI = 1.22–15.52), and increased behavior problem scores on the Child Behavior Checklist (OR = 1.10, 95% CI = 1.05–1.14). Factor analysis of the IPES was also conducted as a comparison with earlier findings in a developed country. We suggest that early monotherapy should be employed whenever possible and that early recognition and treatment of associated psychological problems may help to reduce the burden on families.

Keywords: Epilepsy; Children; Family; Impact

1. Introduction

Globally 50 million people suffer from epilepsy [1], which is the most common neurological disorder affecting children in the developing world [2]. Studies in developed countries suggest that the incidence of epilepsy is around 50 per 100,000 of the general population, whereas in developing countries it is around 100 per 100,000 [1].

The impact of childhood epilepsy has been studied [3–7] and reviewed [8–10] by many authors across the world. They have postulated that the psychosocial impact of epilepsy is multidimensional and related to the severity of epilepsy, to the complexity of clinical management, to restrictions in the child's and family's activities, to the family's innate coping abilities, and to the level of social support and resources available to the family [3].

Few studies, however, have tried to elicit those factors that are particularly associated with increased impact on families who have children with epilepsy. There have been studies that have looked into specific dimensions of the impact associated with psychopathology and with family dynamics in this group of children [11–13], but no robust studies on the impact of pharmacotherapy on the quality of life of patients with epilepsy [14]. Very few studies have used multivariate analyses to determine the relative contributions of the various factors postulated to increase the impact.

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Earlier work done by the current authors demonstrated considerably high psychiatric comorbidity in children with epilepsy in the same setting [15], and we hypothesized that the impact on their families is likely to be multidimensional, involving a complex interaction of demographic, seizure, family environmental, and treatment-related variables.

The research questions we sought to address were:

1. What is the impact of epilepsy on families in a developing country?
2. What are the key determinants and associations of higher impact on families with a child with epilepsy?
3. What would be the factor structure of the Impact of Pediatric Epilepsy on the Family Scale (IPES) in our study when compared with published data from other parts of the world?

2. Methodology

2.1. Procedure

To be included in this study, children had to be 4 to 15 years old, be diagnosed with epilepsy (defined as more than two unprovoked seizures), and not have other significant comorbid medical/neurological conditions. We did not include children who had their first seizure (if they had not been diagnosed to have epilepsy) and children with only febrile seizures. Two hundred and fifty-six patients were screened. Four patients and caregivers did not consent to inclusion in the study. Sixteen patients were excluded based on significant medical comorbidities (6 with severe respiratory system disease, 4 with symptomatic rheumatic disease, 2 with juvenile insulin-dependent diabetes mellitus, 2 with congenital hepatic diseases, and 2 with severe atopic eczema). We did not exclude patients with mild medical conditions such as mild infrequent asthma and asymptomatic cardiac anomalies. None of the cases were excluded based on the presence of psychiatric morbidity.

One hundred and four patients were excluded because of intellectual disability. Most of these patients either had a syndrome associated with learning disability or had a documented IQ score below 70. Only children without intellectual disability were included in the study; the Bharatraj Development Screening Test 1971 [16] for intellectual disability (a modification of the Denver Development Schedule) was used to screen the children. One of the authors had studied the family burden of families with a child with intellectual disability in the same center and had observed that the impact on these families was high [17]. In the current study, we wanted to study impact of epilepsy in particular.

The final sample for the current study consisted of 132 children and adolescents, along with their parents or primary caregivers. If children met the criteria for the study, parents and children were approached and asked for informed consent. Caregivers completed self-report questionnaires. Because some of the caregivers were illiterate, some questionnaires were administered orally (by S.S.D.). The primary caregiver was the mother in 85% of cases. For the remaining 15%, the primary caregiver was the grandmother or elder sister and, for only two children, the father.

2.2. Sample

2.2.1. Sociodemographic profile

The Child Health and Epilepsy clinics serve the large catchment of Vellore District, and patients come from the nearby towns and villages. The median age of the subjects participating in the study was 12, with an interquartile range (IQR) of 8–14. The children had completed a median of 6 years (IQR 3–9) of formal education. The range of family income (rupees per month) was very wide, from 400 rupees ($9) to 30,000 rupees ($674) per month, with a median of 2500 ($56) and an IQR of 1265–8000 ($28–180).

2.2.2. Seizure-related variables

The children recruited for the study had been diagnosed with epilepsy. The median duration since the time of diagnosis of epilepsy was 3 years (IQR 1–7). Time since diagnosis ranged widely and was divided into two groups, above and below the median duration of 3 years, for statistical analysis.

2.2.3. Treatment-related variables

Ninety-three (73%) of the 132 children and adolescents recruited for the study were on monotherapy. The drugs used (in descending order of frequency) were: phenytoin, 51(38.6%); carbamazepine, 33(25.0%); sodium valproate, 32(24.2%); phenobarbital, 26(19.7%); newer drugs, 13(9.8%). Most of the children (70.4%) were relatively stable and had not required hospitalization for seizure-related emergencies during the previous year. We have described the sample in detail in our earlier publication [15].

2.3. Instruments

2.3.1. Assessment of sociodemographic status

Sociodemographics were assessed using a specially designed form. Baseline demographic data and other information including family composition and health services utilization were collected. We included the family composition variable (joint vs nuclear). Traditional (joint) Indian families are composed of parents and grandparents sharing the same house. Often, the extended family, consisting of married male members, their partners, and unmarried women of the parental generation, is included. Although this family composition is common in rural India, the situation is changing quickly in urban areas to a nuclear model, where it is acceptable for both parents to cohabit only with their children. We felt this was a potentially significant variable to include in the study, as the perceived impact on a family with a child with epilepsy might be modulated by the amount of support received by the primary caregivers of the child.

2.3.2. Screening for intellectual disability

As mentioned above, the Bharatraj Development Screening Test (BDST) was used to exclude intellectual disability [16]. The BDST has been standardized for the Indian population in children between the ages of 3 and 16. The BDST was piloted on rural and urban children near Hyderabad and comprises 88 items arranged chronologically according to age-specific abilities. In the BDST, the child and his or her caregiver are asked about the child's abilities; the test takes around 10 minutes to administer. It is a screening instrument that permits exclusion of intellectual disability and is especially suitable for children with psychiatric problems, as it is an observer-rated instrument and has no performance items. It has been used in earlier studies in India [15,18].

2.3.3. Assessment of family environment

Family environment was assessed with the Global Family Environment Scale (GFES) [19], which was used to obtain an overall estimate of the family environment. This instrument rates the family environment on a scale from 0 to 100. The lowest or worst family environment that persisted for a substantial period (at least 12 months) is rated. This worst environment should have begun before 12 years of age. The cutoff point of 12 years was chosen, as it is thought that family environment during adolescence has fewer long-term effects than that during infancy and childhood. Ratings are based as much as possible on objective, positive evidence and not on inference or speculation. Raters seek to use all the information available from all sources to rate the environment. Quality of the environment is rated irrespective of opinions as to who or what might have been the reason for that environment. The lower the score, the more hostile the family environment. This instrument has been standardized across multiple continents, including south Asia [19].

2.3.4. Assessment of seizures and treatment-related variables

Seizure type, frequency, and severity were quantified with a semistructured form. Frequencies of all types of seizures were recorded independently. For uniformity, the frequency of different types of seizures was dichotomized according to internationally accepted guidelines [3]. Patients were considered to have "low-frequency" seizures if they had 1–20 simple partial seizures, 1–4 complex partial seizures, 1 generalized tonic–clonic seizure, or 1–20 absence or myoclonic seizures in the previous 12 months. They were considered to have "high-frequency" seizures if they had more than 20 simple partial seizures, more than 4 complex partial seizures, more than 1 generalized tonic–clonic seizure, or more than 20 absence or myoclonic seizures in the previous 12 months. Seizures were classified according to the International League Against Epilepsy classification system [20].

2.3.5. Assessment of psychopathology

Psychopathology and behavior problems were assessed using the parents' ratings on the Child Behavior Checklist (CBCL) [21]. The CBCL consists of 118 behavior problem items on which the parents rate their children using a 3-point scale, with higher scores reflecting more problems. The CBCL assesses broadband behavior problems (externalizing and internalizing behavior problems) and narrowband behavior problems (attention problems, aggressive behavior, delinquent behavior, somatic complaints, anxiety/depression domain, thought problems, and social problems). Previous research has shown the CBCL to be useful for assessing psychopathology in children with epilepsy [22]. It has been standardized for the Indian population by the National Institute of Mental Health and Neurosciences, Bangalore, under the Indian Council of Medical Research (ICMR) Task Force Study of Child Psychiatric Epidemiology. We used the total CBCL scores for analysis of the data.

2.3.6. Assessment of impact of epilepsy on the family

The psychosocial impact of epilepsy on the child and family was rated with the Impact of Pediatric Epilepsy on the Family Scale (IPES) [3]. This 11-item scale was created for parents to use in evaluating the influence of epilepsy on major aspects of their family and child's life. It takes around 3 minutes for the parent to complete. Each of the 11 items is given a severity score from 0 (not at all) to 3 (a lot). The higher the score, the higher is the impact of that item. The IPES has been found to have good internal reliability, reproducibility, and validity [23].

2.4. Statistical analysis

We intended to study the impact of epilepsy on the families and the associations with "high impact" (Research Questions 1 and 2). For this purpose, the families were divided into two groups, those with low impact and those with high impact, split according to the median score of total impact. The authors of the scale, to study correlates of higher impact, also used this median split method [3]. The median of the total impact score was 2, with an IQR of 0–7.

The IPES was standardized in the Canadian population of Nova Scotia, and the authors published a factor analysis of the 11-item scale [3]. We sought to repeat this analysis to see if it gave rise to similar factors in a developing country (Research Question 3). The data were analyzed using SPSS Version 13 software. In the development of the IPES in the Nova Scotian population, three factors were identified as existing within the scale: outside activity participation (overall health, academic performance, and participation in family and other activities); social well-being (items involving relationships with peers and self-esteem); and home life (relationships with the family). A varimax rotated principal component analysis (PCA) was undertaken to identify factors within the IPES scale in the Indian population.

The IPES yields a total score out of a maximum of 33. Following the median split described above, univariate analyses were carried out to assess the relationship between IPES scores and other potential predictor variables. Mann–Whitney tests were used for continuous variables and χ^2 tests for categorical variables. Nonparametric procedures were used because there was evidence of skew within the data. The continuous variables considered were: age, family income (rupees per month), child education (years), age at onset of epilepsy (years), time since diagnosis of epilepsy (years), time since last seizure (months), GFES score, total number of visits to a doctor in the preceding year, total number of nights hospitalized in the preceding year, and total behavior problem score. The categorical variables considered were: gender, seizure type (focal, focal with generalizations, generalized), seizure frequency (high, low), domicile (rural, urban), religion (Hindu, Muslim, Christian), duration of seizures (<3 years, $\geqslant 3$ years), drug therapy (monotherapy or polytherapy), EEG (abnormal, normal, unknown/not done), and family type (joint, nuclear). Once the potential explanatory variables were identified ($P < 0.1$), a multiple logistic regression model was produced using a stepwise procedure with selection criteria of $P < 0.1$.

2.4.1. Sample size calculation

The current study was part of a larger study [15] for which a sample size calculation was done. In this study on the impact of epilepsy, we repeated the sample size estimation based on the proportion of children receiving polytherapy in the low and high impact groups, and we had sufficient power to be able to detect the difference we observed. The proportion of children on polytherapy in the low impact group was 10% ($n = 68$), and that in the high impact group, 31% ($n = 64$), and at a 5% significance level we achieved 80% power with this.

3. Results

Of the 132 children and families included in this study, 55 (42%) felt at least some adverse impact as rated with the IPES.

3.1. Univariate analysis: associations of higher impact on families with a child with epilepsy

One of the aims of the study was to determine the associations of increased impact of epilepsy on the families of these children. For this purpose, we divided the families into two groups based on the median score of the IPES. We thus had two groups: low impact and high impact. The low impact group ($n = 68$) had a mean IPES score of 0.32 (SD = 0.7), and the high impact group ($n = 64$) had a mean IPES score of 8.80 (SD = 4.9) (Fig. 1).

The children with epilepsy belonging to families who reported high impact were more likely to have a higher frequency of seizures ($\chi^2 = 9.294$, $P = 0.002$) and to be on polytherapy ($\chi^2 = 7.657$, $P = 0.006$). Fewer years since diagnosis of epilepsy ($U = 1748$, $P = 0.051$) and fewer months since last seizure ($U = 1382$, $P < 0.001$) were also associated with high impact. High impact was associated with an increased total behavioral problem score ($U = 954$, $P < 0.001$), internalizing behavioral problem score ($U = 1033$, $P < 0.001$), and externalizing behavioral problem score ($U = 1248$, $P < 0.001$) on the CBCL. Higher total family income ($U = 1768$, $P = 0.062$) was associated with higher perceived impact on the families. There was no difference in the IPES continuous scores ($P = 0.608$), by the Mann–Whitney test, or indeed in the binary case (high impact vs low impact) ($P = 0.865$), by the χ^2 test, when we compared family structure (joint vs nuclear) in the high impact and low impact groups (Tables 1 and 2).

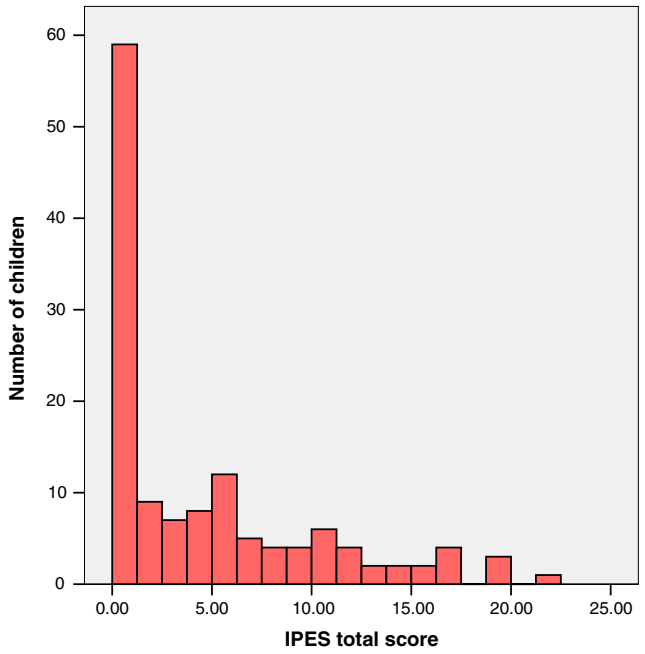

Fig. 1. Total IPES scores of the study group.

3.2. Mutivariate analysis: associations of higher impact on families with a child with epilepsy

The variables identified in the univariate analysis were then entered into a multivariate logistic regression model. A stepwise procedure with an inclusion criterion of $P < 0.05$ and an exclusion criterion of $P > 0.1$ was carried out. The final model had four variables—years since diagnosis of epilepsy, time since last seizure in months, polytherapy, total behavior problem score—which were associated with perceived impact on the families. The unadjusted and adjusted odds ratios (ORs) and their 95% confidence intervals are listed in Table 3.

Adjusting for the other three factors in the model suggests that the risk of being in the high impact group decreases by about 20% for each additional *year* the child has had the seizure disorder and by about 40% for each additional *month* since the last seizure. For each unit increase in the CBCL score, there was a 10% increased risk of being in the high impact group. Polytherapy increased the risk of being in the high impact group by fourfold, compared with monotherapy. When we repeated the analysis using a linear regression model with the impact score as a continuous variable, the same variables were in the final model.

3.3. Principal component analysis

We explored the factor structure of the IPES in a developing country, comparing our findings with the original publication [3]. PCA identified three factors accounting for 68.4% of the variance, with each having eigenvalues of at least one (Table 4).

The first component representing "relationships" accounted for 43% of the variance and was loaded by the items relationships with parents, relationships with siblings, relationships with friends and peers, and acceptability to others (indicated in bold text in Table 4). The second component representing the "optimism factor" (indicated in bold text in Table 4) accounted for 16% of the variance and included the items self-esteem and loss of original hopes of the parent for the child. Finally, the third component, representing "family dynamics," (indicated in bold text in Table 4) accounted for 9% of the variance of the IPES and included the items family activities and relationship between the parents of the child.

Table 1
Families with low and high impact: categorical variables

Variable	Low impact ($N = 68$)		High impact ($N = 64$)		χ^2	P value
	N	%	N	%		
Gender						
Male	43	63	38	59	0.076	0.782
Female	25	37	26	41		
Domicile						
Rural	42	62	34	53	0.685	0.408
Urban	26	38	30	47		
Seizure frequency						
Low	38	56	18	24	9.294	0.002
High	30	44	46	72		
Seizure type						
Primary partial	6	9	3	5	1.264	0.570
Partial with secondary generalization	20	29	23	36		
Primary generalized	42	62	38	59		
Drug treatment						
No drugs/monotherapy	61	90	44	69	7.657	0.006
Polytherapy	7	10	20	31		

Table 2
Families with low and high impact: continuous variables

Variable	Median	(IQR)	Mann–Whitney U	P value
	Low impact ($N = 68$)	High impact ($N = 64$)		
Family income in rupees per month [$/month]	2000 (1000–7000) [45 (23–157)]	3750 (1500–9750) [84 (34–219)]	1768.5	0.062
Age at onset of epilepsy	4.25 (1.63–10.0)	7.75 (3.12–11.5)	1703.0	0.031
Time since diagnosis of epilepsy	3.5 (2–8)	1.0 (0.25–2)	1748.0	0.051
Time since last seizure (months)	3 (1–5)	0.185 (0.08–0.63)	1382.0	<0.001
Global Family Environment Scale (GFES)	90 (90–90)	90 (90–90)	2144.5	0.847
Total number of nights hospitalized in last year	0 (0–1)	0 (0–1)	2118.5	0.743
Total behavior problem score	11.5 (6–24.25)	28 (16.3–58.3)	954.0	<0.001
Internalizing behavior score	2 (1–5)	9 (3–13.75)	1033.5	<0.001
Externalizing behavior score	4 (2–8)	9.5 (5–18)	1248.0	<0.001

Table 3
Multivariate analysis using logistic regression (adjusted and unadjusted): associations of high impact

Variable	Unadjusted		Adjusted	
	OR	95% CI	OR	95% CI
Time since diagnosis of epilepsy (years)	0.89	0.81–0.98	0.81	0.71–0.93
Time since last seizure (months)	0.63	0.46–0.85	0.58	0.39–0.87
Total behavior problem score	1.07	1.04–1.10	1.10	1.05–1.14
Drug therapy (mono-/no therapy, polytherapy)	3.96	1.54–10.18	4.34	1.22–15.52

Table 4
Factor analysis of the 11 IPES items

Loading of items on components	Varimax rotated components		
	Relationships	Optimism	Family dynamics
Overall health	0.186	0.588	0.431
Relationship with parents	**0.791**	−0.061	0.063
Relationship with siblings	**0.845**	0.026	0.270
Relationship between you and your spouse/partner	0.215	−0.038	**0.833**
Relationship with friends/peers	**0.732**	0.341	0.013
Acceptability to others	**0.731**	0.282	0.305
No. of activities	0.482	0.354	0.367
School academics	0.277	0.597	0.391
Child's self-esteem	0.085	**0.922**	−0.035
Your loss of original hopes for your child	0.068	**0.875**	0.129
Family activities	0.122	0.401	**0.730**
Eigenvalues	4.72	1.77	1.03
Rotated % of variance	42.9	16.1	9.4

4. Discussion

Fifty-five families did not feel any impact as rated with the IPES. The risk of being in the high impact group decreased by about 20% for each additional *year* that the child had been diagnosed with seizure disorder and by about 40% for each additional *month* since the last seizure. The adaptation process of the family is likely to determine the impact of epilepsy, and Austin [24] proposed that the adaptation response process evolves with time. Our data support this view. Changes in family demands and resources after seizure onset are likely to influence initial response and impact, whereas longer time since diagnosis of the seizure disorder may have led to better acceptance of the illness and parental encouragement of autonomy. Encouragement of autonomy was significantly associated with a decrease in the total and internalizing behavior problem scores [11], which might be the pathway for decreasing the impact of epilepsy on the family.

In the current study, low impact on the families was associated with a larger number of seizure-free months. Earlier studies have found that quality of life depends on the degree of seizure control [25], and our findings confirm this. Better seizure control may have led to a reduction in parental anxiety and better adaptation of the family.

There have been several studies on the nature and prevalence of psychiatric morbidity in children and adolescents with epilepsy [15,22,26–28] and the impact of psychiatric morbidity on the quality of life of adolescents with epilepsy [29]. There have not been many studies on the impact of psychopathology on the families of this group of children. One study [11] done in North America found that deficient family mastery and parent confidence in managing their children's discipline were associated with behavior problems at baseline and 24 months; these factors also predicted child behavior problems over time in patients with new-onset seizure disorder.

The current study found that each unit change in behavior problem score on the CBCL was associated with a 10% increased risk of being in the high impact group. The association is likely to be bidirectional, with increased impact leading to psychopathology which, in turn, may increase stress on the families. As this was a cross-sectional study, it is difficult to be definitive about causality.

The association of polytherapy with increased behavioral problems has been reported by several authors [15,30,31]. Our study found an independent association between polytherapy and increased impact on the family, even when controlling for the behavior problem score. This finding should be viewed with caution as children on polytherapy might be the ones with more resistant epilepsy. However, as many of the antiepileptic medications act through the same neurotransmitters that are involved in the pathogenesis of psychiatric problems, it is not surprising that polytherapy might have additive effects in producing psychological and physical side effects. This is likely to have an impact on the child and, in a broader way, on the caregivers in the family. However, antiepileptic medications can have both positive and negative effects on a patient's medical and behavioral profile [32], and the choice of a particular medication in epilepsy may depend partly on the behavioral profile of the child. Because the association between medication and behavioral problems can be bi-directional, it is difficult to be definitive about cause and effect in a cross-sectional study, such as the present one.

In the current study, children who were on polytherapy were at a higher risk of being in the high impact group. In an earlier study, Pirio Richardson et al. [33] reported that monotherapy, as compared with polytherapy, was less associated with memory loss, concern over medication long-term effects, difficulty in taking the medications, trouble with leisure time activities, and overall state of health. The need to purchase multiple medications may also financially stress the family. Although a substantial number of our study population were on subsidized treatment, many of them were paying for their treatment, especially for add-on therapies comprising newer, expensive antiepileptic medications. Thus, the association of polytherapy with an increased chance of being in the high impact group can be understood.

There have been interesting reports of improvement in seizure control and quality of life in medically refractory epilepsy patients converted from polytherapy to monotherapy [33].

4.1. Factor analysis of IPES

The IPES had been developed from the original scale by Jacoby et al. [34]. There were no published studies in which the IPES was used within developing countries. A recent review suggested that the psychometric properties of the instruments administered to measure the impact of epilepsy in children and adolescents merit further study [8]. In the original population, the developers of the scale found three factors: "outside activity participation," "social well-being," and "home life" [3]. The results of the current study were quite similar to the original publication [3], with some small differences. In contrast to the original findings of Camfield et al. [3], we found that the relationship items were quite homogeneous and clustered together as one factor, which we called the "relationship factor." "Child's loss of self-esteem" and "parents' loss of hope" were found to reduce to one factor, which we called the "optimism factor"; this finding was interesting, but, perhaps, should be viewed with caution. Response bias (observer and reporting bias) on the part of the caregivers, who were the main informants, may have led to the association of the parents' optimism with the child's optimism. The third factor included "relationship between the parents of the child" and "family activities," which we called the "family dynamics factor." Parents in poorly adapted families had earlier been postulated to be in conflict with each other and to be unable to meet the needs of the child with seizures [24]. A poor relationship between the parents would be likely to interfere with the family's overall participation in any activity together. The factor analysis yielding three factors accounted for 68.4% of the variance of the IPES scale in the current study.

4.2. Limitations

This study was conducted in a tertiary referral center, and the findings may not be generalizable to other settings. The BDST, which we used to exclude intellectual disability, although a popular tool recommended by the National Institute for the Mentally Handicapped (NIMH), Secunderabad, India, has not been widely used. For the current study, because it was the only available screening instrument that had been validated for children in India, we deemed it the most appropriate test.

5. Conclusions

Seizure reduction has been considered to be the most important outcome in this group of children [35]. In recent years, quality of life, impact of epilepsy on the family, psychiatric comorbidities, and stigma issues have received increased attention from researchers [5,14,27,36]. In this study, increased psychopathology score, fewer months since last seizure, fewer years since diagnosis of epilepsy, and polytherapy were associated with a higher impact on families. Unfortunately, psychopathology is still a neglected area of intervention for this group of children, and early identification of psychological problems may help to reduce the impact of epilepsy on families. Because fewer months since the last seizure was also found to be a predictor of high impact on families, optimal seizure control with the minimal number of medications should be the goal wherever possible.

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