Mental health problems in children with uncomplicated epilepsy; relation with parental anxiety

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Mental health problems and parental anxiety in children with epilepsy were investigated. Parents of 83 children with epilepsy and 172 healthy children were asked to complete Strengths and Difficulties Questionnaire for their children and State-Trait Anxiety Inventory for themselves.

In those with epilepsy, 39.8% (n: 33) were girls, 60.2% (n: 50) were boys and their mean age was 9.34 ± 3.99 years. Control group was more successful in school (p<0.001). Emotional problems score in children with epilepsy was higher than control group (p<0.001). Case group's behavior problems and attention deficit hyperactivity scores were higher (p<0.001, p=0.009 respectively). Prosocial behavior scores of the control group were significantly higher (p=0.004). State (p=0.001) and trait (p=0.001) anxiety levels of parents of children with epilepsy were higher.

Children with epilepsy have more neuro-behavioral problems; and their parents have greater anxiety levels. Physicians should be in contact with children with epilepsy for the psychological health of the family besides seizure control.

Key words: ADHD, behavior problems, epilepsy, parent-child interaction.

Epilepsy constitutes the most common serious neurological disorder in children with an estimated prevalence of 0.5-2.2% worldwide^{1, 2}. Children with epilepsy are at significantly higher risk for a range of behavioral and psychiatric disorders including attention deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), depressive and anxiety disorders. Although psychiatric disorders are frequently seen in patients with epilepsy, these disorders usually have been undiagnosed or untreated³⁻⁷. It has been found that at most only one third of the patients with mental disorders receive psychiatric treatment^{6, 7}. Family members of children with a chronic disease are severely affected by the stress caused by this disease. Factors such as lack of social support, financial difficulties and disturbance of domestic life promote this stressful condition. Parents of children with epilepsy are at high risk of having anxiety⁴. There are many recent studies on quality of life of the children with epilepsy and their parents' 4, 8-12. Studies to

address the behavioral/psychiatric problems often associated with childhood epilepsy and its effects on parent's anxiety are lacking³. In this study, we aimed; to determine what proportion of children with epilepsy, who had previously unidentified mental health problems, were found to have such problems on reassessment to compare mental health problems and parental anxiety in children with and without epilepsy.

Material and Methods

Study design and sample selection: This analytical case-control study was conducted in Konya Training and Research Hospital Pediatric Neurology outpatient clinic. The study group included volunteer parents of 83 children with epilepsy between the ages of 4 and 16. The control group consisted of parents of 172 healthy children in similar age group and gender without any chronic diseases. The children were matched, as closely as possible,

for all factors apart from the epilepsy itself. In the case group, the children with known psychiatric disorders, ADHD, any other brain disease, disorder or injury, intellectual disability and using multiple drugs for controlling epilepsy were excluded from the study in order to have an uncomplicated epilepsy group. Regarding the type of seizures, 60.2% of the children (n=50) had generalized seizures and 39.8% (n=33) of them had focal seizures. All subjects had well controlled seizures and they were taking a single antiepileptic drug. Detailed seizure classification is lacking due to the retrospective nature of gathering clinical data from hospital charts.

Data collection: The demographic characteristics questionnaire was created in accordance with literature, and the SDQ (Strengths and Difficulties Questionnaire) scale and STAI (State-Trait Anxiety Inventory) scale were applied to the participants in order to collect the data necessary for the study. The parents were asked to answer SDQ regarding the children's feelings and STAI in terms of their own feelings. The questionnaires were performed by method of face to face interviews with the parents.

Approval of Necmettin Erbakan University Meram Medical Faculty Noninvasive Research Ethics Committee was obtained before starting the study, and written informed consents of the parents who agreed to participate were obtained after given brief information about the purpose of the study.

Sociodemographic Characteristics Questionnaire

Socio-demographic characteristics of the respondents were questioned. The demographic characteristics form included questions regarding: children's age, gender, attendance to school, whether they discontinued the school because of illness, school achievement levels, whether they have been working in a job outside of school, educational level of parents, family income levels, whether the children have siblings, and for the patients group: duration of the disease, type of the seizures, comorbid diseases, and whether s/he displayed self-harming behaviors. In addition, we examined the electroencephalogram (EEG) and brain magnetic resonance imaging (MRI) results of the children to define presence of abnormal findings, by reviewing the hospital records.

Strengths and Difficulties Questionnaire (SDQ)

Strengths and Difficulties Questionnaire (SDQ) was developed by British psychiatrist Robert Goodman¹³. The questionnaire includes 25 questions regarding positive and negative behaviors. These questions were divided into five subheadings each containing five questions which were classified according to the appropriate diagnostic criteria and the factor analysis: emotional symptoms, behavioral problems, attention deficit and hyperactivity, peer problems and prosocial behaviors.

Turkish validity and reliability study of the questionnaire was conducted14. SDQ is an economical and quick solution for scanning the mental health problems frequently encountered in clinical practice. For example, this scale can be used in screening children and adolescents with psychiatric problems by healthcare workers in primary healthcare institutions or in the evaluation of consequences of treatments by the investigators¹⁴. The "Total Difficulties Score" can be calculated by summing the scores of four subheadings as well as each of the subheadings can be evaluated as a separate score. Each question is required to be answered by checking one of the "not correct, partially correct, or absolutely correct" options which have been scored between 0 and 2. The scores for each subscale is the sum of the scores obtained from the questions and ranged between 0 and 10. The total difficulties score ranged between 0 and 40 which is obtained by the sum of the first four subscale scores. Prosocial behavior score is not added to the total difficulties score because conceptually it does not show psychological distress¹⁵. The back page of the questionnaire includes several questions about feelings of the child, gathering attention, behaviors and whether s/he had problems ingetting along with the others. The scores taken from these questions ranged between 0 and 10, and give the impact score. Thus seven different scores were obtained. Each subscale scores are classified as normal. borderline and abnormal according to resulting score calculated by using the cut-off points¹³.

State-Trait Anxiety Inventory (STAI)

The original form of the STAI is in English and was developed by C. D. Spielberger, R. L. Gorsuch and R. E. Lushene. Turkish validity and reliability study was conducted by Öner

and Le Compte, in 1975¹⁶. Scale can be applied to healthy individuals over age of 14 and to patients who are conscious enough to understand and answer what they read. The inventory includes two 20-item subscales: State Anxiety Inventory which defines how individuals feel under certain circumstances at a given time, and Trait Anxiety Inventory which defines how individuals feel regardless of the facts and circumstances they experience.

STAI is a simple, easily applicable inventory that individuals can apply themselves. Scales included straight and reversed expressions. In calculating the scores expressing positive emotions the weighed value of 1 is reversed to 4 and the weighed value of 4 is reversed to one. In scoring the answers of the direct expressions about negative emotions, 4 expressed high level of anxiety. In the reversed expressions the answers scoring 4 indicate low anxiety and

the answers scoring 1 indicate high anxiety. The State Anxiety Scale included 10 reversed expressions (1,2,5,8,10,11,15,16,19 and 20th items), while the trait anxiety scale included seven reversed expressions (21,26,27,30,33,36 and 39th items).

Scoring can be done manually or by utilizing the computer program. We scored manually in which the total weighted scores of the reverse expression is reduced from the weighted scores of the straight expressions and a constant value of 50 for the state anxiety scale, and 35 for the trait anxiety scale is added to the obtained value. The resulting score indicates individual's anxiety levels. Higher scores indicate higher anxiety levels and lower scores indicate lower anxiety levels. The average scores in the applications vary between 36 and 41.

Statistical Analysis

Table I. Comparison of the Sociodemographic Characteristics of Case and the Control Groups

| | Epilepsy cases (N=83) | | Control group (N=172) | | | |
|----------------------|-----------------------|------|-----------------------|------|----------|---------|
| | N | % | N | % | χ^2 | p-value |
| Gender | | | | | | |
| Girls | 33 | 39.8 | 75 | 43.6 | 0.339 | 0.560 |
| Boys | 50 | 60.2 | 97 | 56.4 | | |
| Attendance to School | | | | | | |
| Yes | 64 | 77.1 | 163 | 94.8 | 17.020 | 0.001 |
| No | 19 | 22.9 | 9 | 5.2 | 17.938 | |
| School Absenteeism | | | | | | |
| Yes | 19 | 29.7 | 56 | 34.4 | 0.107 | 0.658 |
| No | 45 | 70.3 | 107 | 65.6 | 0.197 | |
| Achievement Levels* | | | | | | |
| Very Good | 12 | 18.7 | 71 | 43.6 | | |
| Good | 29 | 45.3 | 78 | 47.8 | 33.812 | 0.001 |
| Medium | 17 | 26.6 | 14 | 8.6 | | |
| Bad | 6 | 9.4 | | | | |
| Maternal Education | | | | | | |
| < 8 years | 69 | 83.1 | 106 | 61.6 | 17.296 | 0.002 |
| ≥ 8 years | 14 | 16.9 | 66 | 38.4 | | |
| Paternal Education | | | | | | |
| < 8 years | 52 | 62.7 | 52 | 30.2 | 32.038 | 0.001 |
| ≥ 8 years | 31 | 37.3 | 120 | 69.8 | | |
| Family Income Levels | | | | | | |
| ≤ 400 \$/month | 23 | 27.7 | 15 | 8.7 | 14.965 | 0.001 |
| >400 \$/month | 60 | 72.3 | 157 | 91.3 | | |
| Parents | | | | | | |
| Living together | 76 | 91.6 | 160 | 93.1 | 0.026 | 0.872 |
| Divorced | 7 | 8.4 | 12 | 6.9 | | |

^{*}Based on grades and parental impression

The SPSS 18.0 statistical software package was used in recording and analyzing the data. Descriptive analyses were expressed as mean, median, minimum, maximum values and standard deviation. To define significance the chi-square test and Student's t-test were used. A level of p <0.05 was accepted as statistically significant. Pearson correlation analysis was used in calculation of correlations between total difficulties scores, SDQ subscales scores and trait anxiety scores.

Results

The mean age of the epilepsy group was found to be 9.34 ± 3.99 (ranging between 4-16 years) years and in the control group as 10.10 ± 3.40 (range: 4-16) years. There was no significant difference in terms of mean ages (p=0.119). The comparisons of the demographic characteristics of the groups were shown in Table 1. The mean onset of epilepsy was 6.50 ± 4.35 years and mean duration of epilepsy was 33.10 ± 41.01 months in thechildren with epilepsy.

Regarding attendance to school; the children in the control group attended school more than those in the epilepsy group (p <0.001). The children in control group were more successful in school than those with epilepsy (p <0.001).

Education levels of the parents of the control group were found to be higher and family income levels were better (p <0.001) than the parents of the children with epilepsy. No significant difference were found in terms of living together with the family between the groups (p=0.160). The children with epilepsy had more siblings than their healthy peers (p=0.008). In the study group 10.8% (n=7) of the children had a concomitant disease and 8.4% (n=7) of them used other medications

in addition to epilepsy medications. It was found that 9.6% (n =8) of the children had self-harming behavior and 2.4% (n =2) of them had attempted to commit a genuine suicide.

Regarding the type of seizures, 60.2% of the children (n=50) had generalized seizure and 39.8% (n=33) of them had focal seizures. All subjects had well controlled seizures and they were taking a single antiepileptic drug. Valproate was used in 59% (n=49), carbamazepine in 14.5% (n=12), oxcarbazepine in 1.2% (n=1), levatiracetam in 18.1% (n=15) and other medications were prescribed in 7.2% (n=6) of the patients for manegement of seizures.

In 24.1% (n=20) of the cases, a pathology was detected in the brain MRI and 55.4% (n=46) had normal MRIs, while no brain MRI was taken in 20.5% (n=17) children. The EEG results of the children with epilepsy, showed abnormal electrical activity in 36.1% (n=30) of the children, normal findings in normal pattern in 60.2% (n=50), and EEG was not done in 3 children (3.6%).

When compared in terms of SDQ parameters; emotional symptoms (p <0.001), behavioral problems (p <0.001) and hyperactivity scores (p =0.009) of children with epilepsy were higher than those without epilepsy. No significant difference was found between the groups in terms of peer problems (p=0.063). Prosocial behavior scores were higher in the control group than the case group (p=0.004). Total difficulties and impact scores were significantly higher in the case group than the control group (p <0.001, p=0.002 respectively). (Table II) School drop-out was significantly related with emotional symptoms in CWE (p=0.002) and in the control group (p=0.001).

We found a statistically significant relation

Table II. Comparison of SDQ Parameters Between the Epilepsy Group and Control Group

| | Epilepsy (+) | Epilepsy (-) | | | |
|--------------------------|------------------|-----------------|--------|-----------------|--|
| SDQ** parameters | Mean ± SD* | Mean ± SD | t | <i>p</i> -value | |
| Emotional symptoms | 3.44 ± 2.69 | 2.16 ± 1.87 | 4.398 | 0.001 | |
| Conduct problems | 2.48 ± 2.03 | 1.54 ± 1.57 | 4.029 | 0.001 | |
| Hyperactivity | 4.43 ± 2.44 | 3.60 ± 2.29 | 2.649 | 0.009 | |
| Peer problems | 2.92 ± 187 | 2.50 ± 1.59 | 1.865 | 0.063 | |
| Prosocial behavior | 7.55 ± 2.17 | 8.26 ± 1.61 | -2.935 | 0.004 | |
| Total difficulties score | 13.44 ± 6.67 | 9.81 ± 5.19 | 4.745 | 0.001 | |
| Impact score | 0.89 ± 2.01 | 0.33 ± 0.88 | 3.055 | 0.002 | |

^{*}SD: Standard deviation; **SDQ: Strengths and Difficulties Questionnaire

Table III. Comparison of STAI Parameters Between the Parents of the Children with and Without Epilepsy

| | Epilepsy (+) | Epilepsy (-) | | |
|---------------------|-------------------|------------------|-------|-------|
| STAI*Parameters | Mean ± SD | Mean \pm SD | t | p |
| State anxiety score | 37.71 ± 10.11 | 32.48 ± 7.00 | 4.805 | 0.001 |
| Trait anxiety score | 43.22 ± 8.89 | 38.65 ± 7.42 | 4.317 | 0.001 |

^{*}STAI: State-Trait Anxiety Inventory

between the type of seizures and emotional symptoms, children with generalized seizures had higher abnormal emotional symptoms (p=0.022). The children with focal epilepsy experienced less hyperactivity (p=0.048) and their total difficulties score was lower than those with generalized epilepsy (p=0.024). There were no statistically significant relations between seizure type and children's age, conduct problems, peer problems, prosocial behavior, impact scores and parents' STAI scores (p>0.05). There were no statistically significant relations between seizure type and children's age, conduct problems, peer problems, prosocial behavior, impact scores and parents' STAI scores (p>0.05). There were no statistically significant relations between duration of epilepsy and emotional symptoms, conduct problems, hyperactivity, peer problems, prosocial behavior, total difficulties, impact scores and parents' STAI scores (p>0.05). We found a statistically significant relation between onset age of epilepsy and conduct problems (p=0.016). There were no statistically significant relations between onset age of epilepsy and emotional symptoms, hyperactivity, peer problems, prosocial behavior, total difficulties, impact scores and parents' STAI scores (p>0.05). Families with higher income had statistically significantly more normal scores in emotional symptoms (p=0.021) and peer problems (p=0.013) among children with epilepsy.

State and trait anxiety scores of the parents were statistically significantly higher in the children with epilepsy (p<0.001, p<0.001, respectively) (Table III). It was found that trait anxiety scores of the parents in the epilepsy group were 2.285 times higher than the control group [OR = 2.285 (95% CI: 1.332-3.920)]. We found that in families of control group with higher income trait anxiety levels were statistically significantly lower (p=0.044). Among the parents of children with epilepsy, trait anxiety levels were higher when their children dropped out of school (p=0.007).

Discussion

In this study, we investigated the effect of epilepsy on mental health of children using the SDQ in order to demonstrate that it is a disease that can affect the psychological functioning and behaviors of patients and their families. In addition we used STAI to determine the level of anxiety experienced by parents of children with epilepsy.

In our study, 60.2% of the children with epilepsy were male. The relationship between the prevalence of epilepsy and gender is controversial. Kwong et al¹⁷., showed that the prevalence of the disease was higher among males. Although the majority of the studies made in different regions of Turkey report higher prevalence in males, some studies found no difference between genders¹⁸. In other studies, the prevalence of the disease was higher among females^{19, 20}. Prevalence of active epilepsy was 4/1,000 in females, 7/1,000 in males and 6/1,000 in both groups together in another research²¹.

It has been known that prevalence of epilepsy is higher in countries with lower socioeconomic levels^{22, 23}. In our study, the levels of emotional symptoms and peer problems of children with epilepsy with higher family income were in normal ranges. Trait anxiety levels of the parents with higher incomes were found to be significantly lower.

One of the best indicators of overall compliance for children is adaptation to school. We found that children without epilepsy were more successful in school when compared with the children with epilepsy, meanwhile we found no significant relationship between epilepsy cases and discontinuing school. The school is an important environment for the children to be together with their peers, socializing, developing their talents, and adapting to society²⁴. However children with epilepsy carry a high risk for mental disabilities, learning difficulties, and adjustment problems in school due to seizures, adverse effects of antiepileptic

drugs, frequent hospitalization, overprotective attitudes of parents, emotional problems, and social prejudices^{25, 26}. Therefore, children with epilepsy have been reported to have low school achievement, weak peer relations, and adaptation problems²⁷. In our study, the children with frequent absenteeism have been found be closer to abnormal range in terms of emotional symptoms in both groups. The group with epilepsy have more schooling problems, suggesting that, although the children with intellectual disability were excluded, those who were included may have had at least a mild degree of intellectual impairment.

Lossius et al²⁸., found that attention deficiency and hyperactivity subscale scores of SDQ were higher in the children with epilepsy. Our results also show that the rate of children with epilepsy developing attention deficiency and hyperactivity is higher when compared to healthy peers. Davies et al²⁹., in a study conducted with 5-15 years old British children, found that emotional symptoms, conduct problems, lack of attention and hyperactivity scores were higher in the epilepsy group than the control group. Reference 1, found that children with epilepsy exhibited more emotional symptoms, behavior problems, and hyperactivity than healthy controls¹. However, no statistically significant difference was found between the scores of peer problems. These results are consistent with our results.

Consistent with the literature³⁰, in our study, we found that emotional symptoms, hyperactivity, and total difficulties scores of the children with generalized seizures were highly abnormal. We also found that the behavior problems scores were higher in children diagnosed with epilepsy above six years old than those diagnosed before 6 years old.

Epilepsy constitutes significant psychological stress on families and affects lives of patients in a negative way. It is not easy for families to accept that their children were diagnosed with epilepsy^{31, 32}. In a study investigating self-blame, anxiety and vulnerability perceptions of parents of children with epilepsy, it has been found that anxiety levels of the parents in the study group was higher than the control group in one year after the diagnosis³³. In our study we found that state anxiety levels of parents of children with epilepsy children were 2.12 times higher and trait anxiety levels were 2.28

times higher than the parents of the healthy controls. Trait anxiety levels of the parents of the children who discontinue the school were higher than those whose children continue to the school.

Williams et al³⁴., suggested a relationship between significant anxiety of the parents of the children with epilepsy and reduction in the child's quality of life. In our study, we found that a higher total difficulties score of the children is associated with higher trait anxiety of parents in 21.4% of the children and with state anxiety levels of parents in 13% of the children in the study group.

To our knowledge, this is the first study using SDQ in Turkish children with epilepsy. Also it is the first study comparing mental health problems of children with epilepsy and their parent's anxiety levels by STAI. Limitations of the study were: our study only focuses on uncomplicated epilepsy, there were no teacher or self reported SDQ data and it included the patients and their relatives in a single center. Also this was a clinic-based sample, it is likely to be a highly-selected group, not typical of the general population of children with epilepsy.

Epilepsy syndrome classification is lacking due to the retrospective nature of gathering clinical data from hospital charts. Further research in detailed classified seizure types is needed. The available data shows that children with epilepsy suffer more mental health problems than healthy children. The results of our study confirm that higher rates of psychiatric comorbidity in children with epilepsy may be diagnosed using SDQ. Collaboration between pediatric neurologists and child and adolescent mental health professionals in the assessment and management of children with epilepsy is an essential part of a comprehensive assessment and subsequent development of an intervention program. The increased anxiety levels of parents show that childhood epilepsy affects the mental health of all family members. Therefore preventive measures for protecting mental health should focus not only on the patients but also whole family members.

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