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Original Article / Оригинални рад

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Anxiety and depression in children with new-onset epilepsy: parent vs. child perspectives – six-month follow-up study

Анксиозност и депресија код деце са новодјагностикованом епилепсијом из перспективе деце и њихових родитеља студија шестомесечног праћења

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SUMMARY

Introduction/Objective Common internalizing symptoms, such as anxiety and depression, in school-age children with new-onset epilepsy, may not be immediately evident and can be misinterpreted by parents.

This study compares how school-age children with epilepsy and their parents view the children's anxiety and depression, following previous findings that internalizing symptoms are common six months after diagnosis.

Methods The study was conducted at the University Children's Hospital in Belgrade, Serbia, with assessments performed after diagnosis and again six months later. After obtaining informed consent, children and their parents independently filled out the RCADS questionnaire. Paired t-tests assessed changes in scores from baseline to six months, with $p < 0.05$ considered significant.

Results Throughout the entire group over the six-month follow-up period, all RCADS scores, as well as self-report and parent ratings, showed significant increases. The most notable increases are seen in the subscales of social phobia from self-assessment and panic disorder from parent assessments ($p < 0.01$).

Conclusion Six-month follow-up of internalizing symptoms in our cohort of school-age patients with new-onset, uncomplicated epilepsy has shown that their parents are not sufficiently aware of the symptoms of social phobia, separation, and generalized anxiety, as well as OCD, although their symptoms become significant after six months. Parents need to be taught to recognize their children's emotions and to seek psychological help when necessary.

Keywords: new-onset epilepsy; parents; children; anxiety; depression

САЖЕТАК

Увод/Циљ Уобичајени интернализујући симптоми, попут анксиозности и депресије, код деце школског узраста са новодјагностикованом епилепсијом, често нису очигледни и родитељи их могу погрешно протумачити.Ова студија upoređuje перспективе деце школског узраста са епилепсијом и њихових родитеља везано за доживљај анксиозности и депресије код деце, имајући у виду претходно сазнање да су интернализујући симптоми чести шест месеци након постављања дијагнозе епилепсије.

Методе Студија је спроведена у Универзитетској дечјој болници у Београду, у Србији, у две истраживачке визите, непосредно након постављања дијагнозе и шест месеци касније. Након добијања пристанка, деца и њихови родитељи су самостално попунили стандардизовани упитник Ревидиране скале анксиозности и депресије код деце (РЦАДС). Упарени т-тестови су процењивали промене у резултатима упитника од почетка до шест месеци, при чему се $p < 0,05$ сматрало значајним.

Резултати Током шестомесечног периода праћења, сви РЦАДС резултати, укључујући резултате самопроцене и процене родитеља, показали су значајно повећање. Најзначајнија повећања су примећена у подскалама социјалне фобије на основу самопроцене и паничног поремећаја на основу процене родитеља ($p < 0,01$).

Закључак Шестомесечно праћење интернализујућих симптома у нашој кохорти пацијената школског узраста са новооткривеном, некомпликованом епилепсијом показало је да њихови родитељи нису довољно свесни симптома социјалне фобије, сепарације и генерализоване анксиозности, као и опсесивно-компулзивног поремећаја, иако симптоми постају значајни након шест месеци. Родитељи требају бити упућени у препознавање емоција своје деце како би могли да потраже психолошку помоћ када је то потребно.

Кључне речи: новооткривена епилепсија; родитељи; деца; анксиозност; депресија

INTRODUCTION

It is known that epilepsy in the pediatric population is not just a tendency of the brain to produce epileptic seizures. Children with epilepsy frequently face psychological challenges, which also deeply affect their parents and families [1]. Special challenges are anxiety and depression, which may be hidden at the beginning and often misunderstood by parents [2].

Perceptions of internalizing symptoms in children with epilepsy can vary between observers, with notable differences often seen between parental assessments and the child's self-reports. Parents tend to overlook psychological symptoms, while they are more likely to recognize behavioral disorders [3]. Rielly et al. (2015) showed that symptoms of anxiety and depression from self-report questionnaires are more prominent than parent reports, especially in the areas of anxiety and somatization [4]. Children reported sudden episodes of intense discomfort and a fear of losing control, while parents expressed concern about their children's emotional vulnerability and reactions following these episodes [5]. Conversely, Bal et al. (2021) found that symptoms of anxiety and depression are consistent between parents and children [6]. Baca et al. (2016) also indicated that parents often underestimate symptoms of anxiety and depression in their children with epilepsy, though it remains unclear when these symptoms become more severe [7]. Recognizing these symptoms is crucial because unrecognized symptoms could lead to other consequences, such as reduced quality of life and poor academic performance [8]. Buattour et al. (2021) showed that parents' emotional and psychological state influences their perception of internalizing symptoms in children, with parents more often reporting such symptoms than the children themselves [9].

Earlier, we demonstrated that in school-aged children with new-onset, uncomplicated epilepsy, there are significant levels of internalizing symptoms after six months, mainly due to psychosocial factors at the start and, to a lesser extent, the adverse effects of antiseizure medication [10, 11]. Seizure control, quality of life, cognitive function, and behavioral issues did not influence the increase in anxiety and depression symptoms. When epilepsy is present, these challenges may further add to the burden on families, who are often already dealing with parental anxiety, family functioning difficulties, and stress related to the unpredictability of seizures [12]. However, to better support both children and parents, a broader perspective is necessary. Since issues may arise early during epilepsy, it is important to examine the background. Therefore, the present study aimed to systematically explore anxiety and depressive symptoms from the perspectives of children with epilepsy and their parents to help develop guidelines for preventing internalizing symptoms in children with epilepsy.

METHODS

The research was conducted at the University Children's Hospital in Belgrade, Serbia, during the first half of 2020. It was part of a larger research project that also examined quality of life, behavior, and cognition [10, 11]. Data collection was conducted using a test–retest design in two phases: the initial assessment at the time of epilepsy diagnosis and a follow-up assessment six months later. The baseline results obtained at diagnosis served as the control for comparison with those collected after 6 months. The inclusion criteria included school-age children with a newly diagnosed non-structural epilepsy (confirmed by EEG and brain MRI), normal psychomotor and cognitive development until then, and no other chronic illnesses. Participants in the study were all children consecutively recruited.

Children and their parents, after signing informed consent, completed the Revised Children's Anxiety and Depression Scale (RCADS) during two visits. They completed the RCADS separately to prevent influence from one on the other.

The RCADS has both self-report and parent/guardian rating versions. Each version has 47 questions evaluating symptoms: 31 for anxiety, 10 for depression, and 6 for obsessive-compulsive disorder (OCD). All questions are on a Likert scale from 0 (never) to 3 (always), and the total score for each subscale is the sum of responses. Six subscales measure specific symptoms: social phobia, separation anxiety disorder, panic disorder, generalized anxiety disorder, depression, and OCD. There is also a total anxiety score (sum of the first four subscales) and a total internalizing symptoms score (sum of anxiety and depression). A higher score indicates increased severity of general and specific symptoms. Psychometric research has demonstrated that the questionnaire yields reliable and valid assessments of these symptoms, and the Serbian version was employed in this study [13].

Descriptive statistics included absolute values, percentages, mean values (M), and measures of dispersion such as standard deviation (SD) and standard error (SE). Inferential statistics involved Paired t-tests to examine differences in questionnaire scores at baseline (before) and after six months (after). Normality of the data distribution was assessed using the Shapiro–Wilk test. The effect sizes of significant changes were expressed using Cohen's d coefficient and interpreted as low (< 0.5), medium (0.5–0.8), or high (> 0.8) [10]. All analyses were performed with IBM SPSS Statistics 18, and p-values of less than 0.05 were considered statistically significant.

Ethics: The study adhered to ethical principles and the Helsinki Declaration, following the decision of the Ethical Committee of the University Children's Hospital, University of Belgrade, Belgrade, Serbia (No: 13/208).

RESULTS

In the research, only adequately completed data obtained from completed questionnaires were analyzed. The Shapiro–Wilk test, accompanied by visual inspection of histograms and Q–Q plots, indicated that the data met the assumption of normality. After the second visit, data were available for 60 children and their parents, because three children were lost to follow-up and five needed another ASM after the initial therapy, which was the exclusion criterion. There was no statistical difference in the results of questionnaires between those who were excluded and the included children at the first visit, as well as in age, gender, number of seizures, or levels of intelligence ($p < 0.05$).

Demographic and basic clinical details are presented in Table 1. The average age of the respondents at the time of inclusion in the study was 12.32 (SD = 3.34) years, ranging from 7 to 18 years (Table 1). Concerning the initial number of seizures before the introduction of ASM, a statistically significant reduction is observed after six months ($z = -4.52$; $p < 0.01$), which is highly clinically relevant ($r = 0.58$).

Throughout the entire group over the six-month follow-up period, all RCADS scores, along with self-report and parent ratings, showed significant increases (Tables 2 and 3). The effect sizes are high for most scales ($d > 0.8$). The most notable increases are seen in the subscales of depressive disorder and social phobia from self-assessment, and panic disorder from parent assessments. Comparison between self-reported and parent-reported RCADS scores is presented in Figure 1.

DISCUSSION

This is the first study to compare the experience of internalizing symptoms in children with new-onset epilepsy immediately after diagnosis and after six months, from both parents' and children's perspectives. We found that even at the start, parents tend to downplay their children's anxiety symptoms, which tend to become more noticeable over six months. The findings are concerning, especially as *social phobias* become the most common anxiety symptom in children after follow-up. Blocher et al. (2015) have shown that 20% of school-aged children with epilepsy were diagnosed with clinically significant social phobia, developing after several years of living with epilepsy, primarily from the children's perspectives [14]. Considering that social phobias in children involve an intense and persistent fear of social situations where the child expects evaluation, rejection, or ridicule, and can severely affect the child's emotional development, self-confidence, and daily functioning—particularly in school and social settings—our results highlight the need for prevention [15]. Although parents might not realize that social situations can easily trigger anxiety in their children with epilepsy, the epileptologist guiding the child has a responsibility to address it.

In the study by Schwarze et al. (2017), *panic disorder* was the most common anxiety disorder among children with epilepsy [16]. However, we found that parents are less aware of panic disorder initially compared to children. After six months, this dynamic shift and the most significant change in children's experience of panic disorder are observed in their parents, as if they become more aware, possibly because panic disorder is more clinically visible than social phobias. This can be explained by studies from Kwong et al. (2016) and Kim & Kim (2022), which showed that children exhibited more severe symptoms of social anxiety and irritability, while parents focused more on the more obvious clinical symptoms [17, 18].

On the other hand, the *child's separation anxiety* is more visible to the parents at the beginning and more pronounced after six months, which is not surprising considering that it is most often directed towards the parents. In a longitudinal study of children with recently diagnosed epilepsy, nearly one-third of children met the requirements for separation anxiety, which is significantly higher than in the general population, according to parents' reports. In contrast, the prevalence of other anxiety disorders was substantially lower, making separation anxiety the most common single type of anxiety early in the course of illness [19]. It should be highlighted that separation anxiety persists into adulthood, and overprotection is a predictor of lower quality of life [20]. Separation anxiety also reduces the caregiver's independence, highlighting a two-way relationship [21].

What is also surprising is that children are more aware of their *OCD symptoms*. In analogous research on pediatric OCD, parents report significant distress, uncertainty about their child's future, and burden**,** especially when symptom severity is high and family accommodation occurs [22]. In cases of comorbid epilepsy and pediatric OCD, parents often face compounded emotional strain, not only from managing the neurological unpredictability of epilepsy, but also from navigating their child's OCD symptoms [23]. It seems that in the case of children with epilepsy, obsessive thoughts are also conscious, and that at the beginning, and especially after 6 months. OCD includes not only thoughts, but also actions, which parents can misinterpret as perfectionism [24]. That emphasizes the need for psychological support. Kasak et al. found that having a child with epilepsy negatively affects parents' mental health, parent–child relationships, family dynamics, and parental coping styles, so a bidirectional relationship is clear [25].

Even after 6 months, when it is significantly expressed, parents notice less *generalized anxiety* than their children, which is not surprising since generalized anxiety can often be hidden.

Generalized anxiety disorder in children is characterized mainly by difficult-to-control worries about everyday topics (such as school performance, health, and family dynamics), often accompanied by somatic symptoms like tension, fatigue, and disturbed sleep, which seriously affect their daily functioning and psychological well-being [15].

Parents may mistake it for *depressive symptoms*, which, according to our results, are initially more noticeable to them than from the patients' perspective. However, after six months, children become very aware of their depressive feelings. Bearing that in mind, there is growing concern: does a parent's expression of a child's feelings influence them, passing their worries to the child? This aligns with findings from Rosic et al. (2020), which show that in longitudinal studies, children's depressive symptoms are reflected in their assessments, while they initially exhibit more anxiety; conversely, parents display the opposite pattern [26]. Additionally, Goldstein et al. (2024) demonstrated that over time, children's and parents' perceptions of anxiety symptoms become similar, indicating that the symptoms become interconnected [27].

Our findings extend previous evidence showing only moderate agreement between children and parents when reporting anxiety and depressive symptoms in pediatric epilepsy by demonstrating that these discrepancies persist and become more clinically relevant over time [28]. Reliance on parental reports alone may therefore result in under-recognition of emerging internalizing symptoms, notably less observable anxiety domains. Routine inclusion of standardized child self-report measures during early follow-up may facilitate timely identification of psychopathology. Integrating systematic psychological screening and targeted parent psychoeducation into standard epilepsy care could improve long-term mental health and overall clinical outcomes.

Unfortunately, in this study, we did not compare psychological difficulties in children with other chronic illnesses. We know that parents of children with epilepsy fear night seizures and separation, such as during school trips, and their children share these fears. However, is this fear more intense than that experienced by parents and children with asthma and diabetes mellitus? Additionally, it has been shown that parents of children with diabetes face depression or psychological stress, worries about long-term recovery, complications, and daily disease management [29]. Consequently, depression and anxiety are more common in these children than in healthy peers: about one-third display depressive symptoms and anxiety, which can significantly complicate the disease course, as psychosocial stress also worsens metabolic control and quality of life [30]. Similarly, children with asthma, along with their parents, fear asthma attacks, worry about treatment, symptoms, and physical limitations such as sports and school activities, and often experience anxiety and depression [31]. Children tend to exhibit anxiety symptoms, especially related to attacks or activity restrictions; they also face a risk for depression, although parental attitudes may influence how these symptoms are perceived [32]. Nonetheless, we can agree that no pediatric chronic illness is associated with stigma to the extent that epilepsy is.

CONCLUSION

A six-month follow-up of internalizing symptoms in our cohort of school-age patients with new-onset, uncomplicated epilepsy revealed that their parents are not sufficiently aware of symptoms like social phobia, separation anxiety, generalized anxiety, and OCD. However, these symptoms become more pronounced after six months. In this study, we did not conduct a more detailed analysis of how parents' experiences affect their children's symptoms, which we consider a significant limitation. Additionally, we did not examine other factors related to epilepsy or background factors that might contribute to internalizing symptoms. Nonetheless, we want to highlight the importance of parent education. Psychologists and epileptologists also play a role in helping parents understand their child's emotional experiences while managing epilepsy.

Conflict of interest: None declared.

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Table 1. Basic demographic and clinical data of the subjects

Parameters	**At beginning** M (SD), n = 68	**After six months** M (SD), n = 60
Age (SD), range	12.32 (3.34), 7–18	12.45 (3.25), 7–18
Male/female, n (%)	38 (55.9)/30 (44.1)	34 (56.7)/26 (43.3)
Seizure control		
Complete	36 (52.9)	35 (58.3)
Partial	19 (27.9)	20 (33.3)
Poor	13 (19.2)	5 (8.3)

Table 2. Self-report of Revised Children's Anxiety and Depression Scale (RCADS) questionnaire scores in the follow-up period (n = 60)

Subscale	**At beginning** M (SD)	**After six months** M (SD), d
Self-assessment		
Social phobia	4.90 (3.58)	9.12 (4.66)*, 1.22
Panic disorder	2.15 (2.48)	5.18 (4.39)*, 1.12
Separation anxiety disorder	1.85 (2.39)	3.48 (3.42)*, 0.88
Generalised anxiety disorder	2.57 (2.63)	5.25 (3.27)*, 0.83
Total anxiety disorder	11.47 (8.54)	23.03 (13.11)*, 1.30
Depressive disorder	2.50 (2.00)	6.77 (4.64)*, 1.81
Total internalizing	13.97 (9.66)	29.80 (16.76)*, 1.52
Obsessive-compulsive disorder	1.63 (2.58)	3.53 (3.28)*, 0.74

*p < 0.01 from paired t-tests

d – Cohen's coefficient

Table 3. Parent-report of Revised Children's Anxiety and Depression Scale (RCADS) questionnaire scores in the follow-up period (n = 60)

Subscale	**At beginning** M (SD)	**After six months** M (SD), d
Parent-assessment		
Social phobia	5.35 (3.01)	7.73 (4.25)*, 0.97
Panic disorder	1.42 (1.29)	3.25 (3.34)*, 1.27
Separation anxiety disorder	2.00 (2.55)	2.98 (3.67)*, 0.59
Generalised anxiety disorder	2.35 (1.81)	3.90 (2.74)*, 0.78
Total anxiety disorder	11.02 (6.05)	17.87 (10.88)*, 1.22
Depressive disorder	2.93 (2.22)	6.15 (4.21)*, 1.81
Total internalizing	13.95 (7.49)	24.02 (14.33)*, 1.36
Obsessive-compulsive disorder	1.52 (1.64)	2.32 (2.38)*, 0.53

*p < 0.01 from paired t-tests

d – Cohen’s coefficient

Figure 1. Comparison between Revised Children's Anxiety and Depression Scale (RCADS) scores from self-report and parent report