Epilepsy & Behavior 112 (2020) 107454

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

The perceived health of children with epilepsy, sense of control, and support for their families

Eva Vrščaj [a], Mirjana Perković Benedik [a,b], Jasna Oražem Mrak [a], Neli Bizjak [a], Damjan Osredkar [a,b,*]

[a] Department of Pediatric Neurology, University Children's Hospital, University Medical Centre Ljubljana, Slovenia
[b] Faculty of Medicine, University of Ljubljana, Slovenia

ARTICLE INFO

Article history:
Received 4 April 2020
Revised 25 August 2020
Accepted 27 August 2020
Available online xxxx

Keywords:
Epilepsy
Children
Perceived health
Control
Support

ABSTRACT

Aim: The aim of this study was to evaluate the perceived health of children with epilepsy as experienced by the respondents to a questionnaire, to assess the sense of control over their child's epilepsy, and how much support they feel they received in various environments.
Methods: In this observational study, the data were collected using a questionnaire that was sent to families of children with epilepsy, who were treated at University Children's Hospital in Ljubljana, Slovenia from January to September 2016. The questionnaire consisted of 29 questions related to their epilepsy.
Results: There were 1198 patients who met the entry criteria for the study and were sent the questionnaire, of which 181 (15.1%) responded. The diagnosis of epilepsy was established in 91.2% of patients (8.8% were patients after a first unprovoked seizure), of which drug-resistant epilepsy was reported in 33.3%. Patients had epilepsy diagnosed for a mean of 4.9 ± 4.4 years. Of all patients, 82.4% of patients were taking antiepileptic drugs (AEDs) at the time of inquiry. The longer the patient had epilepsy diagnosed, the lower was the perceived health ($p = 0.004$). Patients with pharmacoresistant epilepsy, those who had seizures, and those who were receiving AEDs had significantly lower scores of perceived health compared with those who did not ($p < 0.001$; $p < 0.001$; and $p = 0.016$, respectively). Of all responders, 79.8% responded that they feel that they have their child's condition under control. The child's condition was considered under control more often if the child had no reported seizures ($p < 0.001$) and if the family had enough support in the health system ($p = 0.002$) or psychological support ($p = 0.005$). Patients with pharmacoresistant epilepsy more often replied that they do not have enough support in the health system ($p = 0.006$).
Conclusions: Our study suggests that the presence of seizures, pharmacoresistant epilepsy, years of epilepsy diagnosis, and prescription of AEDs have a significant negative effect on the perceived health of children with epilepsy. Enhancement of the support families received in different environments can offer an opportunity to improve the sense of caregivers' control over child's epilepsy.

1. Introduction

Epilepsy is globally the fifth most burdening neurological disease [1], with the annual cumulative incidence of 67.8 per 100,000 persons [2] and the incidence of epilepsy in children in the range of 41–187/100,000 [3]. In majority of patients, epilepsy begins in childhood, and approximately 50–60% of children with epilepsy reach complete remission of seizures at some point in life [4]. Epilepsy may be related to psychiatric, behavioral, and cognitive comorbidities, with consequent long-term negative effects [5]. Children with epilepsy can also have compromised health-related quality of life (HRQoL) [6], with the family environment playing a major role in child's HRQoL [7]. The child's epilepsy can pose a heavy burden for the family, with the main family concerns usually being related to seizure control, school performance, and side effects of medication, and many parents feel that they need more information on their child's epilepsy [8]. Parents' perceptions of their children's HRQoL can be lower than those for other chronic illnesses, especially for refractory epilepsy [9].

Successful treatment of epilepsy requires, among others, the correct antiepileptic drug (AED) selection for the specific etiology, the optimal AED dose, and patient's compliance. Interventions for improved self-management can also lead to improvements in HRQoL of children with epilepsy, as well as parent's fears and anxieties [10]. Mothers of young children with epilepsy report high levels of parenting stress and higher levels of difficulties with parent–child interaction, which were not associated with epilepsy factors, compared with that of mothers of children with nonepilepsy-related neurodisability [11]. Parenting stress is negatively related to quality of life of children with

* Corresponding author at: Department of Pediatric Neurology, University Children's Hospital, University Medical Centre Ljubljana, Bohoričeva 20, 1525 Ljubljana, Slovenia.
E-mail address: damjan.osredkar@kclj.si (D. Osredkar).

https://doi.org/10.1016/j.yebeh.2020.107454
1525-5050/

epilepsy, independently of important confounders, such as perceived economic status, seizure frequency, and perceived severity of the disease [12]. However, parents of children with new-onset epilepsy are likely to positively recalibrate their assessments of their children's HRQoL over a 1-year period after diagnosis, i.e., report better HRQoL, even though their clinical symptoms have not necessarily improved [13]. The response shift in parents' perception of HRQoL of children with new-onset epilepsy can be used in targeted interventions to improve patients' perception of different aspects of their HRQoL. In a study by Ryan et al. [14], low degree of concordance between parents' and physician's perceptions for various aspects of epilepsy has been found, but evidence suggested that satisfaction with care may be positively related to degree of concordance.

Perceived health of children with epilepsy as seen by their caregivers was not extensively studied before. The aim of this study was to evaluate perceived health of children with epilepsy as experienced by the respondents to a questionnaire, to assess the sense of control over their child's epilepsy, and how much support they think they receive in various environments. To our knowledge, there are no published studies that would examine the perceived health of children with epilepsy, as seen by the caregivers, although perceived health might have important influence on the burden the child's epilepsy poses for the family. We have related perceived health of the patients and sense of control over their child's epilepsy with different variables such as years of epilepsy, presence of seizures, pharmacoresistant epilepsy, and prescription of AEDs.

2. Methods

In this observational study, the data were collected using a questionnaire that was sent to families of children with epilepsy or those who had their first unprovoked seizure, who were treated at our pediatric neurology department of the University Children's Hospital in Ljubljana, Slovenia, from January 1st to September 30th, 2016. Our epilepsy center is a tertiary referral center treating the most severe pediatric epilepsy cases in Slovenia. The patients were treated either at the inpatient or outpatient units of our department. If the patients were seen at our department more than once in the designated period of time, they were asked to respond to the questionnaire regarding the last visit only.

All patients were sent a questionnaire consisting of 29 questions related to their epilepsy (Appendix A). We did not use a previously studied questionnaire as such questionnaire was not published before. The set of questions we have used in the questionnaire was what we believed were the most relevant questions to the studied topic of perceived health, sense of control, and support for families of children with epilepsy. The caregivers or patients themselves were able to respond over a web-based form or over regular mail. The questionnaire responses were anonymous, and the patients and their families were informed about this in the introduction of the questionnaire. Basic questions about patients, such as age and sex, were listed at the beginning of the questionnaire. Next were questions related to clinical characteristics of their epilepsy, such as year of diagnosis of epilepsy, number of seizures per unit of time, whether the epilepsy is pharmacoresistant, treatment with AEDs, etc. Next were questions related to how healthy the caregivers perceive their child is and how happy they were with the evaluation and care at our department. Next, the questionnaire included questions about the support the patients and their caregivers receive in the health system, school, organizations for patients with epilepsy, the family environment, and psychological support. At the end of the questionnaire, the participants had the opportunity to comment on the quality of the healthcare they have received at our hospital. They were also asked if they thought they had situation under control.

For questions that required a score, a scale of 1–10 was used, where 1 represented poor/not satisfied at all and 10 represented excellent/very satisfied.

Statistical analyses were performed with SPSS version 26 (SPSS Inc., Chicago, USA). Descriptive variables were presented as number of cases and percentage of the whole. Chi square analysis was used to compare the categorical groups of patients. Linear regression was used to analyze the relationship between years of diagnose of epilepsy compared with the perceived health of the patient (given as B value and 95% confidence interval (CI)). Logistic regression was used to analyze the relationship between years of diagnose of epilepsy compared with sense of control over epilepsy. Independent sample T-test was used for group comparisons when evaluating the differences in between perceived health between patients with or without pharmacoresistant epilepsy; presence or absence of seizures; treatment with or without AEDs; the fact that patients had or did not have enough time to discuss child's problems with the physician; and the fact whether they did or did not receive enough information/support regarding child's health problems at the last follow-up (p-value and 95% CI of the difference in means were given). Chi-square test was used for group comparisons as above when evaluating the differences in the sense of control over the disease.

The mean age of patients and the mean duration of epilepsy (since diagnosed) were given as years ± standard deviation.

A statistical value of $p < 0.05$ was considered significant.

The study was approved by the Slovene National Ethics Committee (0120-185/2018/7).

3. Results

There were 1198 patients who met the entry criteria for the study and were sent the questionnaire, of which 181 (15.1%) responded. Most participants responded over the web-based form.

Summary of the patient data is presented in Table 1. There was a slightly higher percentage of male patients (55.1%). The questionnaire was completed by parents in 88% (156 in total, 133 by mothers and 23 by fathers), by the patients themselves in 11% (20 in total), and by other close relatives in 1%. Children of all ages were included in the study; the mean age of children in the study was 10.6 ± 5.6 years. The detailed distribution by age is shown in Table 1.

The families who responded, came to our hospital either for the first time (6.3%) or for a follow-up examination (93.7%). About one-third of

Table 1
Clinical characteristics of enrolled children with epilepsy/first unprovoked seizure. The numbers vary between different fields as not all respondents responded to all questions.

Characteristics	N	%
Age		
0–5	42	23.6
6–10	46	25.8
11–15	44	24.7
16–18	30	16.9
18+	16	9.0
Sex		
Female	97	44.9
Male	79	55.1
Number of seizures		
None	79	43.6
Less than one per month	35	21.1
One per month	7	4.2
More than one per month	5	3.0
One per week	6	3.6
More than one per week	6	3.6
One per day	5	3.0
More than one per day	23	13.9
Pharmacoresistant epilepsy		
No	90	55.6
Yes	54	33.3
Uncertain	18	11.1
Antiepileptic drugs		
No	30	17.6
Yes	140	82.4

the patients (36.0%) were hospitalized during the visit, and the rest (64%) of them were seen at the outpatient clinic.

The diagnosis of epilepsy was established in 91.2% of patients (the remaining 8.8% patients had a first unprovoked seizure), of which drug-resistant epilepsy was reported in 33.3%. The mean time interval between the diagnosis of epilepsy and the follow-up was 4.9 ± 4.4 years. The longest period since the diagnosis made was 19 years, and the shortest period was less than a year. Of all patients, 82.4% of patients were taking AEDs at the time of inquiry.

Of all respondents, 166 gave their answers about number of seizures; 79 (47.6%) did not report to have seizures, 87 (52.4%) patients had at least one per month or more, and 15 patients (8.3%) did not answer to that question. Comparison of patients with seizures and patients without is presented in Table 2.

3.1. Perceived health of patients

When asked how healthy the child was in respondent's opinion (1 poor health, 10 excellent health), the children received a median score of 8 (minimum 1, maximum 10; Fig. 1). The longer the patient had epilepsy diagnosed, the lower was the perceived health score of the respondent ($p = 0.004$; B −0.118; 95% CI for B from −0.199 to −0.037). Patients with pharmacoresistant epilepsy had significantly lower scores compared with those who did not have pharmacoresistant epilepsy (mean: 6.09 vs 8.31, respectively; $p < 0.001$; 95% CI of the difference 1.50–2.94; Fig. 1). Also, patients who had seizures had significantly lower scores compared with those who did not have seizures (mean: 6.46 vs 8.65, respectively; $p < 0.001$; 95% CI of the difference 1.53–2.84; Fig. 2). This was true also within the subpopulation of patients, who did not have pharmacoresistant epilepsy — the presence of seizures was related to lower perceived health of the child (mean: 7.36 vs 8.68; $p = 0.001$; 95% CI of the difference 0.53–2.11). Moreover, patients who were receiving AEDs also had significantly lower scores compared with those who did not received them (mean: 7.23 vs 8.41, respectively; $p < 0.016$; 95% CI of the difference 0.23–2.15). Perceived health was higher when respondents thought they had their child's epilepsy under control, compared with those who did not feel so (7.81 vs 6.09, respectively; $p < 0.001$; 95% CI of the difference 0.83–2.62) or if they felt that the physician was adequately treating their child's epilepsy, compared with those who did not feel so (7.71 vs 6.30, respectively; $p = 0.012$; 95% CI of the difference 0.33–2.49).

Perceived health was not related to whether the respondents thought they had enough time to discuss child's problems with the physician at the last follow-up or not (7.59 vs 6.79, respectively; $p = 0.11$; 95% CI of the difference −1.77–0.17) or if they have received enough information on their child's health condition or not (7.77 vs 6.83; $p = 0.29$; 95% CI of the difference −0.91–2.78).

Perceived health was higher when the respondent reported that the child had enough support in the health system or not (7.84 vs 6.86, respectively; $p = 0.010$; 95% CI of the difference 0.24–1.72), by the psychologists (7.94 vs 6.93; $p = 0.006$; 95% CI of the difference 0.29–1.74), or patient organizations (7.95 vs 6.79; $p = 0.004$; 95% CI of the difference 0.37–1.95); but was not significantly related to the amount of support in the home environment or school environment.

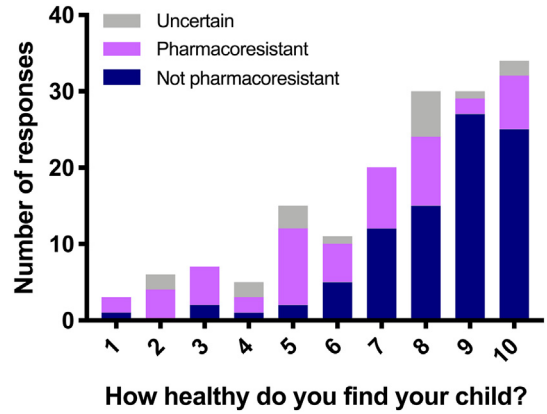

Fig. 1. The perceived health of children with diagnosed epilepsy as reported by caregivers. The groups were separated by whether the child's epilepsy was pharmacoresistant or not. Pink — pharmacoresistant epilepsy; blue — epilepsy not classified as pharmacoresistant; gray — caregivers were uncertain whether the patient has pharmacoresistant epilepsy. Scale 1 to 10: 1 poor health, 10 excellent health. (For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.)

3.2. A sense of control over the health condition

Of all participants, 79.8% (N = 138) responded that they feel that they have their child's condition under control and 20.2% (N = 35) responded they do not feel that way.

The opinion that the child's condition was under control was significantly related to the number of seizures. If the child had no seizures, significantly more respondents reported that they had the child's condition under control ($p < 0.001$). Also, significantly more respondents felt that they had their child's epilepsy under control if the child's epilepsy was not pharmacoresistant ($p < 0.001$). Sense of control was not related to the fact whether the child was treated with AEDs or not ($p = 0.80$) or to the years of epilepsy diagnosis ($p = 0.15$).

The respondents felt that they had their child's epilepsy under control more often if they thought they received enough information on their child's health condition ($p = 0.017$). Of all respondents that thought they have the condition under control (N = 138), 122 (87.8%) said that the child's physician was adequately treating child's condition, 15 (10.8%) that he/she was not, and 2 (1,4%) did not give an answer. Of the respondents that thought they do not have the condition under control (N = 35), 17 (48.6%) said that the child's physician was adequately treating child's condition, 15 (42.9%) that he/she was

Table 2
Comparisons between the patients with and without seizures. * marks significant differences in answers.

		Patients with seizures	Patients without seizures
Number of patients		87	79
Mean age (years ± SD)		10.5 ± 5.6	11.5 ± 5.5
Mean duration of epilepsy (years ± SD)		5.4 ± 4.9	4.6 ± 4.3
Number of patients who receive AED		76 (87.4%)	63 (79.7%)
How healthy do you find your child?	*	6.2 ± 2.5	8.7 ± 1.6
Do you feel that you have a child's health condition under control? (Yes)	*	63 (73.4%)	75 (94.9%)
Do you think that child's epilepsy is well managed by the doctor? (Yes)	*	62 (72.9%)	73 (92.4%)
Do you think that your family has enough support in the health system? (Yes)	*	47 (54.7%)	57 (72.2%)
Do you think your family has enough support in school? (Yes)		57 (70.4%)	60 (78.9%)
Do you think that your family has enough support in organizations (e.g., Slovenian League Against Epilepsy)? (Yes)	*	36 (48.0%)	42 (64.6%)
Do you think that your family has enough support in your home environment? (Yes)		70 (81.4%)	64 (81.0%)
Do you think that parents have enough support on the psychological side? (Yes)	*	42 (51.2%)	53 (67.1%)

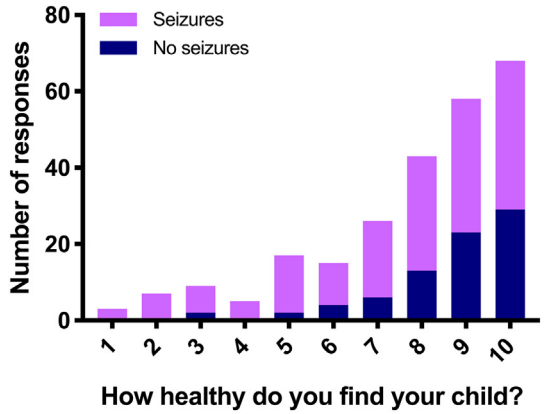

Fig. 2. The perceived health of children with or without seizures at the time of last visit to our department. Pink — seizures present; blue — no seizures. Scale 1 to 10: 1 poor health, 10 excellent health. (For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.)

not, and 3 (8.5%) did not give an answer. This difference was statistically significant ($p < 0.001$).

The opinion that the child's condition was under control was also related to whether the respondent reported that the child had enough support in the health system ($p = 0.002$) or by the psychologists ($p = 0.005$) but was not significantly related to the amount of support in the home environment, school environment, or patient organizations.

3.3. Support for the children with epilepsy and their families

The questionnaire included questions regarding support the family and patients received in the health system, school, patient organizations, family environment, and psychological support. The support was not precisely defined but was meant as a general supportive approach to the patient and families and tending to their special needs in a particular environment in question. By psychological support, we asked whether they felt that the psychological burden of the disease was adequately addressed by professionals.

The summary of results regarding support is shown in Table 3. As expected, the most supportive was the home environment, as it received the highest number of positive answers (81,6%). The question regarding sufficient support in school was answered as sufficient in 74.5%, in the health system in 62.5%, psychological support for patients and families was assessed as sufficient in 58.2%, and support by patient organizations in 54.9%.

When we compared patients with seizures with patients without any seizures, the respondents of children who had seizures have significantly more often said that they do not have enough support in the health system ($p = 0.017$), psychological support ($p = 0.027$), or patient organizations ($p = 0.033$), which was not true for the support in the home environment ($p = 0.853$) or school environment ($p = 0.230$). For patients with pharmacoresistant epilepsy, the respondents significantly more often replied that they do not have enough support in the health system ($p = 0.006$), while they found enough support in other environments and psychological support.

Table 3
Satisfaction with the support the enrolled families of children with epilepsy receive in various environments.

Question	Answer	N	%
Do you think that your family has enough support in your home environment?	Yes	142	81.6
Do you think your family has enough support in school?	Yes	123	74.5
Do you think that your family has enough support in the health system?	Yes	110	62.5
Do you think that parents have enough support on the psychological side?	Yes	99	58.2
Do you think that your family has enough support in patient organizations?	Yes	78	54.9

4. Discussion

The purpose of this questionnaire-based study was to evaluate the perceived health, sense of control, and support the children with epilepsy/families receive in their environments. Epilepsy is a multifaceted disease, and there are many possible approaches to improving life of patients with epilepsy. Parental perception of their child's epilepsy was not extensively studied before as there are only few studies published on the topic [8,14–16], and ours is the first to elucidate such relationships in a European country. However, understanding and targeting parental perception by therapeutic approaches might have important positive consequences for the families who are suffering from their child's epilepsy. Our study suggests that the presence of seizures, pharmacoresistant epilepsy, prescription of AEDs, and years of the diagnosis of epilepsy have a significant negative effect on the perceived health of children with epilepsy. However, the response rate to the questionnaire used in our study was 15.1%, which is an important limitation of the study. Some of the results therefore cannot be generalized to the whole population, as it is likely that responders gave different answers that the nonresponder would.

The findings of our study suggest that patients who had seizures had significantly lower scores compared with those who did not have seizures at the time of evaluation. Also, significantly lower perceived health scores in patients with pharmacoresistant epilepsy compared with those who did not have pharmacoresistant epilepsy, which was expected. Our results also suggest that the longer the patient has had epilepsy, the lower the perceived health score was, and that the fact that the child received AEDs also reduced the perceived health score. In the study by Ramsey et al., the number of AEDs was also found to be the most consistent predictor across various HRQoL domains (such as physical, emotional, neurocognitive, social) and of overall HRQoL [17]. As other authors have highlighted, the effect of the seizures is significantly connected with the parental fear for the children. During a seizure, they are frightened, and they can experience panic, and even fear the possibility of death [18–21]. Perceived health in our study was also higher when the respondents thought they had their child's epilepsy under control and when they reported that the child had enough support in the health system, by the psychologists, or patient organizations, which is an important point as it offers the possibility for therapeutic intervention.

We also explored the sense of control of the respondents over their child's health condition. Of all respondents that thought they have the condition under control, 87.8% said that the child's physician was adequately treating child's condition. Of the respondents that thought they do not have the condition under control, only 48.6% said that the child's physician was adequately treating child's condition. These findings suggest that parental view of their physician's work is strongly related with the sense of control over the disease. The sense of control over epilepsy was also related with the support these families get in the health system and psychological support. The correlation between child's and parent's perception was not tested in our study and is an interesting topic for further research, but in children with epilepsy, the correlation of child and parental HRQoL perceptions was excellent in the study of Haneef et al. [9], while other studies find that child–parent reports are not interchangeable [22,23].

In the study of Jones et al. [24], parents were generally satisfied with the initial information they received about seizures and their management but reported that the association between epilepsy and

neurobehavioral issues was often not broached. One of the encouraging findings in our study was that patients received enough support in the home environment (81,6%), in school (74,5%), and in the health system (62.5%). The only subgroup of patients who did not get enough support in the healthcare system in our study were patients with pharmacoresistant epilepsy. The findings of our study are encouraging as studies have shown that children with epilepsy have more functional difficulties and limitations in school, compared with children without epilepsy [25–28]. Contrary, we cannot be totally satisfied with the results regarding the psychological support and the support by patient organizations. Support from these two parties is undoubtedly essential for improving the HRQoL for people with epilepsy and their families. Jones et al. also noted that parents would like informational and emotional support to extend beyond the time of epilepsy diagnosis [24]. The findings of our study are in accord also with the findings of Kwong et al. [8], that enhancement of networks among relevant organizations is needed to offer better support to families with children with epilepsy.

Our study has several limitations. As already mentioned, of all patients, we have received the answer from 181 (15.1%) patients, which might be too small a number for the sample to be representative of the whole population [29]. Also, the questionnaire did not thoroughly inquire about patients' epilepsy and standardized items of HRQoL, which would provide more detailed information on how well the families cope with the condition. We have used a self-constructed questionnaire to evaluate perceived health of patients; however, a standardized protocol would be a more valuable and essential tool for further studies of this topic. Furthermore, 11% of the questionnaires were answered by patients. Although most of the patients were children and have most likely responded to the questionnaire in the presence/accordance with their parents, it is known that responses can differ between children and their caregivers, which we have not corrected in our analysis.

Living with epilepsy poses many challenges, but the desire by parents and children for a 'normal' childhood is of major importance to both [30]. Understanding how children with epilepsy and their parents perceive their condition, what alleviates their concerns, and where they get most support from warrants further studies.

To conclude, our study suggests that the presence of seizures, pharmacoresistant epilepsy, years of epilepsy diagnosis, and prescription of AEDs have a significant negative effect on the perceived health of children with epilepsy. Enhancement of the support families receive in different environments can offer an opportunity to improve the sense of caregivers' control over their child's epilepsy, which can translate to improved HRQoL of children with epilepsy. Based on our study, we conclude that further, more systematic studies of perceived health of child's epilepsy and sense of control over the disease are warranted for better care for families with children who have epilepsy.

Declaration of competing interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Appendix A. Improving the experience of children with epilepsy

Dear parents,

At the Pediatric neurology department of the University Children's Hospital in Ljubljana, we would like to improve the care and medical treatment of children and adolescents with epilepsy. In order to do so, we kindly ask you for your cooperation.

We would like to know more about your experience on your last visit at the Department, what you liked, what you didn't and what would you change to make your experience better. Therefore, we kindly ask you to fill in this questionnaire.

Your answers will be completely anonymous and will be used solely to improve the experience of children and adolescents with epilepsy and their families at future check-ups.

We truly thank you for your cooperation.

The questions related to the child and epilepsy.

Who is filling the questionnaire?

- Mother
- Father
- Child
- Other relative

The age of the child:

- Less than 1 year
- 1 year
- 2 years
- 3 years
- 4 years
- 5 years
- 6 years
- 7 years
- 8 years
- 9 years
- 10 years
- 11 years
- 12 years
- 13 years
- 14 years
- 15 years
- 16 years
- 17 years
- More than 18 years

The gender of the child

- Female
- Male

Has your child been diagnosed with an epilepsy? (If not, please omit the following questions that are directly related to the epilepsy)

- Yes
- No

Year of diagnosis of epilepsy?

How many seizures does the child have nowadays?

- More than one per day
- One per day
- More than one per week
- One per week
- More than one per month
- One per month
- Less than one per month
- None

Is your child's epilepsy defined as pharmacoresistant (meaning that the disease does not respond to medication)?

- Yes
- No
- I don't know

Does your child receive antiepileptic drugs?

- Yes
- No

How do you evaluate the health status of your child, from 1 to 10? (1 means very sick, 10 means perfectly healthy).

Questions related to the experience on your last visit at the Department.

Did the child come to the first visit or check-up?

- The first patient treatment
- The check-up

Was the child treated in inpatient or outpatient units of our department?

- Inpatient unit
- Outpatient unit

General satisfaction with the care at our department, from 1 to 10? (one means very unsatisfied, 10 means very perfectly satisfied)

Did the doctor have an appropriate approach towards your family, from 1 to 10?

(1 means very unappropriate, 10 means perfectly appropriate).

Did the health staff have an appropriate approach at our department, from 1 to 10?

(1 means very unappropriate, 10 means perfectly appropriate).

Did you feel like you had enough time to talk to your doctor?

- Yes
- No

It seemed to me that we got enough information about:

	Do not agree	Partly agree	Agree
The child's health condition			
Child's epilepsy			
The diagnostics investigations carried out so far			
The plan of further investigations			
The treatment plan			
Prescribed medications			
Life with epilepsy			
How to treat a child in the future			
What epilepsy means for her/his school			
How to get additional help			
What to do if the situation worsens			

Do you think that child's epilepsy is well managed by the doctor?

- Yes
- No

Do you feel that you have a child's health condition under control?

- Yes
- No

Is your child treated by psychologists at our department?

- Yes
- No

Do you think that your family has enough support in the health system?

- Yes
- No

Do you think your family has enough support in school?

- Yes
- No

Do you think that your family has enough support by organizations (e.g., Slovenian League against epilepsy)?

- Yes
- No

Do you think that your family has enough support in your home environment?

- Yes
- No

Do you think that parents have enough psychological support?

- Yes
- No

What did you like during the last visit at our department?

What did you miss during the last visit at our department?

What you did not like during the last visit at our department?

What would you do differently during the last visit at our department to make your experience better?

Would you like to say to us something else what could improve the management of children with epilepsy at our department?

Thank you very much for your cooperation!

With your help, we will improve the experience and treatment of children and adolescents with epilepsy and their families.

References

[1] Feigin VL, Nichols E, Alam T, Bannick MS, Beghi E, Blake N, et al. Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol. 2019;18:459–80. https://doi.org/10.1016/S1474-4422(18)30499-X.

[2] Fiest KM, Sauro KM, Wiebe S, Patten SB, Kwon C-S, Dykeman J, et al. Prevalence and incidence of epilepsy: a systematic review and meta-analysis of international studies. Neurology. 2017;88:296–303. https://doi.org/10.1212/WNL.0000000000003509.

[3] Camfield P, Camfield C. Incidence, prevalence and aetiology of seizures. Epileptic Disord. 2015;17:117–23. https://doi.org/10.1684/epd.2015.0736.

[4] Camfield PR, Camfield CS. What happens to children with epilepsy when they become adults? Some facts and opinions. Pediatr Neurol. 2014. https://doi.org/10.1016/j.pediatrneurol.2014.02.020.

[5] Baca CB, Vickrey BG, Caplan R, Vassar SD, Berg AT. Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. Pediatrics. 2011;128. https://doi.org/10.1542/peds.2011-0245.

[6] Puka K, Tavares TP, Anderson KK, Ferro MA, Speechley KN. A systematic review of quality of life in parents of children with epilepsy. Epilepsy Behav. 2018;82:38–45. https://doi.org/10.1016/j.yebeh.2018.03.008.

[7] Ferro MA, Camfield CS, Levin SD, Smith M Lou, Wiebe S, Zou G, et al.. Trajectories of health-related quality of life in children with epilepsy: a cohort study. Epilepsia. 2013;54:1889–97. https://doi.org/10.1111/epi.12388.

[8] Kwong K, Wong S, So K. Parental perception, worries and needs in children with epilepsy. Acta Paediatr. 2007;89:593–6. https://doi.org/10.1111/j.1651-2227.2000.tb00344.x.

[9] Haneef Z, Grant ML, Valencia I, Hobdell EF, Kothare SV, Legido A, et al. Correlation between child and parental perceptions of health-related quality of life in epilepsy using the PedsQL.v4.0 measurement model. Epileptic Disord. 2010;12:275–82. https://doi.org/10.1684/epd.2010.0344.

[10] Fleeman N, Bradley PM. Care delivery and self-management strategies for children with epilepsy. Cochrane Database Syst Rev. 2018;2018. https://doi.org/10.1002/14651858.CD006245.pub4.

[11] Reilly C, Atkinson P, Memon A, Jones C, Dabydeen L, Das KB, et al. Parenting stress and perceived stigma in mothers of young children with epilepsy: a case–control study. Epilepsy Behav. 2018;89:112–7. https://doi.org/10.1016/j.yebeh.2018.10.016.

[12] Im YJ, Il Cho Y, Kim DH. Family management style as a mediator between parenting stress and quality of life of children with epilepsy. J Pediatr Nurs. 2019;45:e73–8. https://doi.org/10.1016/j.pedn.2018.12.007.

[13] Sajobi TT, Speechley KN, Liang Z, Goodwin SW, Ferro MA, Wiebe S. Response shift in parents' assessment of health-related quality of life of children with new-onset epilepsy. Epilepsy Behav. 2017;75:97–101. https://doi.org/10.1016/j.yebeh.2017.07.015.

[14] Ryan BL, Speechley KN, Levin SD, Stewart M. Parent's and physicians' perceptions of childhood epilepsy. Seizure. 2003;12:359–68. https://doi.org/10.1016/S1059-1311(02)00325-4.

[15] Kinkar A, Alqarni D, Alghamdi A, Wali S, Alghamdi N, Saloom S, et al. Parental knowledge, attitudes, and behaviors toward their epileptic children at King Abdulaziz University Hospital: cross-sectional study. Interact J Med Res. 2020;9:e12697. https://doi.org/10.2196/12697.

[16] Rani A, Thomas PT. Parental knoweldge, attitude, and perception about epilepsy and sociocultural barriers to treatment. J Epilepsy Res. 2019;9:65–75. https://doi.org/10.14581/jer.19007.

[17] Ramsey RR, Loiselle K, Rausch JR, Harrison J, Modi AC. Predictors of trajectories of epilepsy-specific quality of life among children newly diagnosed with epilepsy. Epilepsy Behav. 2016;57:202–10. https://doi.org/10.1016/j.yebeh.2016.02.002.

[18] Rutter N, Metcalfe DH. Febrile convulsions — what do parents do? Br Med J. 1978;2:1345–6. https://doi.org/10.1136/bmj.2.6148.1345.

[19] Camfield P, Camfield C. Sudden unexpected death in people with epilepsy: a pediatric perspective. Semin Pediatr Neurol. 2005;12:10–4. https://doi.org/10.1016/j.spen.2004.11.005.

[20] Baumer JH, David TJ, Valentine SJ, Roberts JE, Hughes BR. Many parents think their child is dying when having à first febrile convulsion. Dev Med Child Neurol. 1981;23:462–4. https://doi.org/10.1111/j.1469-8749.1981.tb02019.x.

[21] Balslev T. Parental reactions to a child's first febrile convulsion. Pediatr Infect Dis J. 2006;10:877. https://doi.org/10.1097/00006454-199111000-00024.

[22] Baca CB, Vickrey BG, Hays RD, Vassar SD, Berg AT. Differences in child versus parent reports of the child's health-related quality of life in children with epilepsy and healthy siblings. Value Heal. 2010;13:778–86. https://doi.org/10.1111/j.1524-4733.2010.00732.x.

[23] Ronen GM, Rosenbaum PL, Boyle MH, Streiner DL. Patient-reported quality of life and biopsychosocial health outcomes in pediatric epilepsy: an update for healthcare providers. Epilepsy Behav. 2018;86:19–24. https://doi.org/10.1016/j.yebeh.2018.05.009.

[24] Jones C, Atkinson P, Memon A, Dabydeen L, Das KB, Cross JH, et al. Experiences and needs of parents of young children with active epilepsy: a population-based study. Epilepsy Behav. 2019;90:37–44. https://doi.org/10.1016/j.yebeh.2018.10.031.

[25] Pastor PN, Reuben CA, Kobau R, Helmers SL, Lukacs S. Functional difficulties and school limitations of children with epilepsy: findings from the 2009–2010 National Survey of Children with Special Health Care Needs. Disabil Health J. 2015;8:231–9. https://doi.org/10.1016/j.dhjo.2014.09.002.

[26] Reuben CA, Pastor PN. The effect of special health care needs and health status on school functioning. Disabil Health J. 2013;6:325–32. https://doi.org/10.1016/j.dhjo.2013.03.003.

[27] Thies KM. Identifying the educational implications of chronic illness in school children. J Sch Health. 1999;69:392–7. https://doi.org/10.1111/j.1746-1561.1999.tb06354.x.

[28] Joe S, Joe E, Rowley LL. Consequences of physical health and mental illness risks for academic achievement in grades K-12. Rev Res Educ. 2009;33:283–309. https://doi.org/10.3102/0091732X08327355.

[29] Taherdoost H. Determining sample size; how to calculate survey sample size. Int J Econ Manag Syst. 2017;2:237–9.

[30] Harden J, Black R, Chin RFM. Families' experiences of living with pediatric epilepsy: a qualitative systematic review. Epilepsy Behav. 2016;60:225–37. https://doi.org/10.1016/j.yebeh.2016.04.034.