MATHEWS JOURNAL OF NEUROLOGY

MATHEWS Open Access Journals

Research Article

ISSN: 2572-6536

Vol No: 4, Issue: 2

Received Date: Nov 18, 2019

Published Date: Dec 3, 2019

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Does the Quality of Life Study Reflect the Sociodemographic Background of Epileptic Children and Adolescents?

ABSTRACT

Aim: Health related quality of life (HRQoL) and social background were assessed in children and adolescents with epilepsy and was compared with control children.

Method: Children's HRQoL was self-reported with the KIDSCREEN-52 questionnaire. 144 families with an epileptic child and 237 families from the general population were enrolled.

Results: Children with epilepsy and their parents rated their quality of life poorer than their counterparts did in the general population. The 8-12-year-old children had higher scores than the adolescents. The parents' opinions about their children with epilepsy were poorer than the reports of their children. There were no significant sex differences. The age, intensifying seizure frequency, polytherapy had a negative influence on six parts of the HRQoL. Well-treated epilepsy means a better quality of life. Interestingly, the duration of epilepsy had less influence. Family background regarding the parent's occupation, education, marital status, large families was very disabled of children with epilepsy.

Conclusion: Our study was based on the perspectives of children with epilepsy, not just on the opinions of their parents. Socio-demographic characteristics justify the disadvantage of parents and families caring for an epileptic child.

Keywords: Epilepsy; Quality of Life; Children; Adolescents; Parents; Seizure Frequency.

Abbreviations: HRQoL: Quality of life; E: Epilepsy; GP: General Population; Ch: Children; P: Parent; ES: Effect Size; r: Pearson Correlation; p: Significance Level; SD: Standard Deviation; L: Least Frequent; F: Less Frequent; MoF: More Frequent; MF: Most Frequent; ILRE: Idiopathic Localization-Related Epilepsy; IGE: Idiopathic Generalized Epilepsy; SGE: Symptomatic Generalized Epilepsy; SFE: Symptomatic Focal Epilepsy; AED: Antiepileptic Drug.

INTRODUCTION

Epilepsy has been a well-known, frequent disease from ancient times. Its acceptance depends on the society, community and historic times. There have even been cultural differences between countries and continents throughout the ages [1-11].

In the last 20 years, a better understanding of epileptogenesis, the discovery

DOI: https://doi.org/10.30654/MJN.10017

of antiepileptic drugs, the rapidly evolving neuroimaging techniques and the development of epilepsy surgery have enormously improved the therapeutic options for epilepsy. Patients with well-controlled epilepsies have a better chance for a happy, satisfied life [12,13].

Our null hypothesis was that well-established epilepsy without comorbidities would not significantly reduce the quality of life compared to the general population. A prospective clinical non-interventional case-series study with parental and general population controls was designed. Similar studies on the HRQoL of epilepsy have been performed in many countries in both children and adolescents [1-9,14-29], but the results of these studies are sometimes controversial; therefore, we wanted to assess HRQoL in Hungarian children as well.

METHODS

HRQoL Questionnaires

We administered the KIDSCREEN-52 questionnaire, which is a generic, validated paediatric HRQoL instrument designed for healthy and chronically ill children and adolescents [30,31]. Parents were also asked to fill in their version of the questionnaire.

We designed a statistically representative population with 100 families with an epileptic child (E) and 200 families from the general population (GP).

Social demographic data were collected about education, occupation, family relationship of parents, number and diseases of sibling. Education was classify in three level: below or equivalent 8 class, secondary education and highly educated parents. Occupations were studied in 2 main groups: active and inactive status (unemployment, housewife, pensioner/retired, student). Family relationships were living together/joint family (married or cohabitation) and nuclear family (divorced, widowed, single). Patients and GP were collected from 4 counties of Hungary so there were not enough patients of groups to measure regional differences.

Patient population

Data were collected between November 2012 and February 2015. The 144 children aged 8-18 years with epilepsy were prospectively recruited in two regional paediatric medical centres. The study focused on the HRQoL of children and adolescents with epilepsy from two geographical regions of Hungary: the South-West (patients at the Department of Paediatrics of the University of Pécs) and the North-East (Borsod County Hospital). The necessary data were collected from clinical/hospital databases.

Those children with epilepsy and one of their parents who presented themselves at a neurological follow-up visit were asked to fill in the questionnaires. The questionnaires were generally filled in at their home and were sent back by post. Children were not recruited during hospitalization to avoid influence on the HRQoL evaluation during a period with particular stress, anxiety or pain. Each child had to able to complete the questionnaire by her/himself. Patients with severe motor or intellectual disability were not recruited. Children with mild mental retardation were not excluded, but it was essential that the child/parent could understand the questions and answer them clearly. All patients were treated with antiepileptic drugs, none were on a ketogenic diet or had undergone epilepsy surgery.

Two main age groups were created as follows: 8-12 and 13-18 years. Throughout this study, when children and adolescents were considered together, they were collectively called 'children'. The main characteristics of the children's epilepsy were also collected as follows: classification of their epileptic seizure/syndrome was according to ILEA criteria [32,33] and duration of epilepsy was recorded in years.

The following four categories of seizure frequency were used: least frequent (maximum 1 a year or seizure free), less frequent (1 or 2 per month), more frequent (≥ 3 per week), and most frequent (daily). The number of antiepileptic drugs that were taken simultaneously by the children (1 = monotherapy; 2-3 = polytherapy).

General population

General population data were collected from randomly selected urban and rural primary and high schools of Borsod County and catchment areas of the University of Pécs (Baranya, Tolna and Somogy Counties), which corresponds to the areas covered by the two hospitals from which the E sample was recruited. Finally, the total number of participants was 268 for statistical validity.

Statistical analysis

We compared the groups across all 10 dimensions of KIDSCREEN as follows:

1. The scores of the GP groups with KIDSCREEN values
2. The scores of the children with epilepsy (E) and their parents with the general population groups (children and parents also);
3. For the E groups: parents with children; child and adolescent reports; boys with girls; correlations and significances between age, duration of epilepsy and seizure frequency; influence of age, duration time of epilepsy, seizure frequency and antiepileptic drug therapy (monotherapy or polytherapy).

Statistical analysis was performed using licensed IBM SPSS statistics version 24 software. Where KIDSCREEN-52 items were negatively formulated, they were recoded, as recommended by the test developers, so that higher values indicated higher HRQoL [30,31]. Questionnaires with more than 10% missing values were omitted. The items were summed and averages were calculated for each dimension score and a total score.

We used ANOVA descriptive statistics to investigate significant differences between the mean scores of different groups, paired sampled *t*-tests and *F*-tests. A Chi squared probe showed whether a significant correlation existed between the variables. Cross tabulation was used to determine correlations and significances between the main variables (HRQoL, age, seizure frequency, duration of E, and drug therapy). The confidence interval (CI) was 95% and significance was set at $p < 0.05$. The strength of correlation (r) was: weak = 0-0.25, medium weak = 0.25-0.5, medium strong = 0.50-0.75, or strong = 0.75-1. For establishing statistical significance, $p < 0.05$ was used.

For measuring effect sizes (ES), Cohen's d was used, which defines the difference between two means divided by the standard deviation for the data. ES values were very small d = 0.01; small 0.2; medium 0.5; large 0.8; very large 1.2; and huge 2.0.

Risk rate was calculated to analyse socio- demographic variables. The risk ratio was considered significant with a ± 20% difference. (RR: CI_E/CI_{GP}; CI: Cumulative incidence of E or GP)

Ethics

Approval was obtained from the Regional Science Ethical Committee of the University of Pécs and from the Regional/ Local Committee of Science and Research Ethics of Borsod-Abaúj-Zemplén, Heves and Nógrád Counties. Informed consent was obtained from the children and their parents.

RESULTS

Baseline characteristics

We invited every child with epilepsy (E) from our databases who was able to fill in the test to participate. Descriptive information is in **Table 1.**

Table 1: Descriptive information on groups with epilepsy (E) and the general population (GP).

Variable	Epilepsy No (%)	GP No (%)
Total	144 (100)	237 (100)
8-12 years	59 (40.97)	113 (47. 68)
13-18 years	85 (59.03)	124 (52.32)
Age (mean ± SD)	15 y 7 mo ± 3.5 mo	12 y 11 mo ± 7 mo
Sex		
Male	78 (54.17)	115 (48.52)
Female	66 (45.83)	121 (51.48)
Parental tests filled in by		
Mother	127 (88.19)	207 (87.34)
Father	11 (7.64)	22 (9.28)
Other relatives	6 (4.17)	6 (2.53)
Epilepsy syndromes	**No.**	**%**
ILRE	35	24.3
IGE	64	44.13
SGE	4	2.76
SFE	33	22.76
Duration of E (mean ± SD)	4 y 3 mo	2 y 11 mo
AED therapy	**No.**	**%**
Monotherapy	96	66.7
Polytherapy	39	27.1
Unknown	9	6.2
Total	144	100

Abbreviations: No.: Number of respondents, SD: Standard deviation, %: Percent, y:Year, mo: Month. ILRE: Idiopathic localization-related epilepsy, IGE: Idiopathic generalized epilepsy, SGE: Symptomatic generalized epilepsy, SPE: Symptomatic focal epilepsy, AED: Antiepileptic drug.

The data given by the general population were validated for the KIDSCREEN values. The values of GP parents did not differ practically from those of KIDSCREEN. Interestingly, the social acceptance (bullying) values of the Hungarian GP children were higher than the European average. Bullying was less common in both the general and the E population than in the KIDSCREEN European population. We consider that using both

of our GPs was applicable **(Tables 2 and 3)**.

Quality of life of children with epilepsy compared to the Hungarian general (control) population **(Tables 2 and 3)** summarize the mean KIDSCREEN scores given by the children and their parents from the general population (GP) and from the epileptic (E) population (children with epilepsy and their parents). All children with epilepsy and their parents rated their HRQoL lower than that of the general population [*p* (Ch, P) = 0.002 and 0.009. respectively].

Table 2: Mean T-values and their standard deviations of children and their parents of general population and children with epilepsy and the relevant effect sizes (KIDSCREEN to GP and GP to E).

Questions	Item	GP Children				E Children				GP Parents				E Parents			
		N	T	±SD	ES-1	N	T	±SD	ES-2	N	T	±SD	ES-3	N	T	±SD	ES-4
Sum	52	237	51.68	8.6	0.17	144	50	9.2	0.19*	237	54.10	8.60	0.06	144	51.73	8.4	0.29*
Physical Well-being	5	236	52.9	14.4	0.29	144	49.5	13.6	0.24*	236	52.30	12.20	0.03	144	47.58	10.6	0.41**
Psychological Well-being	6	236	53.6	13.8	0.36	144	51.5	15.4	0.15*	236	59.00	11.20	0.12	144	51.20	12.8	0.66*
Moods & Emotions	7	235	55.3	10.6	0.53	144	53.3	13.2	0.17	235	53.20	8.60	0.04	144	52.34	10.4	0.09**
Self-Perception	5	236	46.2	4.2	-0.38	144	45.2	4.6	0.23*	236	52.60	11.20	0.03	144	50.52	13	0.17*
Autonomy	5	236	52.2	17	0.22	144	52.5	16.4	-0.02	236	50.60	15.20	0.01	144	51.17	14.6	-0.04
Parent Relation & Home Life	6	236	53.4	12.6	0.34	144	53	12.8	0.03	236	53.60	12.40	0.05	144	52.40	11.8	0.10
Financial Resources	3	236	52.9	21.6	0.28	144	49.2	22.4	0.17**	236	54.00	20.40	0.05	144	50.18	20.6	0.19**
Social Support & Peers	6	236	53.8	16.8	0.38	144	53.2	18.2	0.03	236	53.90	15.00	0.05	144	52.50	17.4	0.09
School Environment	6	236	55	15.8	0.5	144	55.2	16	-0.01*	236	54.20	13.20	0.06	144	51.43	14.2	0.20*

Abbreviations: N: Number of population, SD: Standard deviation, GP: General population, E: Epileptic population, T: mean T-value *: p< 0.05, **p<0.001, Sum: summary of the ten KIDSCREEN dimensions. ES-1: Cohen effect sizes between KIDSCREEN and GP, EF-2: Cohen effect sizes between GP and E children. ES-3 Cohen's effect sizes between KIDSCREEN and GP, EF-4: Cohen's effect sizes between GP and E parents.

Table 3: Relationship of various patient characteristics: Child-parent correlations and significance, age and gender scores and their significance.

Dimensions	Children-Parent		Age					Gender				
			8-12 years		13-18 years			Male		Female		
	r	ES-5	T-value	±SD	T-value	±SD	ES-6	T-value	±SD	T-value	±SD	ES-7
Sum	0.703**	-0.23	50.64	9.4	48.81	8.8	0.20	50	8.4	48.96	10.2	-0.15
Physical Well-being	0.552	0.18	52.40	12.2	48.87	12	0.27*	50.61	11.2	51.58	13.6	0.06
Psychological Well-being	0.641	0.02	51.19	12.4	48.61	14.8	0.17	49.34	12.6	50.63	15.6	0.25
Moods & Emotions	0.564*	0.09	50.00	12.6	49.72	13.8	0.02	50.00	11.2	49.90	15.2	0.24
Self-Perception	0.434**	-0.63	41.26	4.4	40.13	4.6	0.25*	44.67	4.6	44.10	4.6	0.16
Autonomy	0.569	0.10	49.75	17.8	50.90	15.8	-0.07	51.32	15	49.71	18.2	0.26
Parent Relations & Home Life	0.613	0.06	52.34	10.4	48.70	13.6	0.28*	51.76	12.4	49.6	13.2	0.06
Financial Resources	0.687	-0.05	45.60	22	45.47	22.8	0.01	45.80	23.6	47.81	20.6	0.18
Social Support & Peers	.682**	0.05	49.62	19.2	49.77	17.6	-0.01	49.45	18	50.00	18.4	0.41
School Environment	0.666**	0.29	52.19	16.8	50.89	15	0.08*	51.20	15.2	48.52	17.2	0.05
Social Acceptance	0.724**	-0.32	47.09	13.2	45.98	12.8	0.09	46.60	14.2	45.98	11.4	-0.15

Abbreviations: *r*: Pearson correlation. significance: *: $p < 0.05$. **$p<0.001$. SD: Standard deviation. mean: Mean KIDSCREEN scores. Sum: Summary of the ten KIDSCREEN scores ES: Cohen's effect sizes. ES-5: CH-P effect sizes. ES-6: children-adolescents effect sizes. ES-7: Male-female effect sizes.

Self-reported HRQoL scores were significantly lower in the "E" children in five of ten dimensions, i.e., physical well-being, psychological well-being, self-perception, financial resources and social acceptance ($p \leq 0.05$). Effect sizes were small values in these domains except for the social acceptance domain, where the ES was very large. Children with epilepsy considered their financial resources worse than their peers from the general population (p = 0.000) **(Table 2)**.

We found a large difference in the opinions of parents of the children with epilepsy and parents of children from the

general population. They assessed the HRQoL of their children similarly in only three dimensions (autonomy, parent relations and home life and social support and peers). The ESs were in small and medium ranges (0.17-0.41), but physical well-being had the highest ES (0.66) **(Table 2)**.

The self and parent proxy-reports were in agreement. Answers of children and their parents were in a medium-strong positive significant relationship regarding moods and emotions and self-perception dimensions ($0.4 < r < 0.6$). The correlations were stronger than the medium range, which were also in a positive direction, in social support and peers, school environment and social acceptance dimensions ($0.65 < r < 0.73$). Self-perception and social acceptance were rated poorer by children than parents with medium level ES. It seems that the school environment had larger effects on HRQoL as reported by parents than by children ($p \leq 0.01$) **(Tables 2 and 3)**.

A significant difference was found considering the HRQoL of children according to age. The 12-18-year-old population had poorer scores in four of ten dimensions, i.e., physical well-being, self-perception, parent relations and home life and school environment ($p < 0.05$) in these dimensions. ESs were mainly small in these domains **(Table 3)**.

There were no significant differences between the sexes in the HRQoL of children with E **(Table 3)**.

Other variables

Variables that were included in the cross-tabulation were as follows: age, duration time of epilepsy, seizure frequency and the ten dimensions of HRQoL levels. In **Table 4**, only variables with significant correlations are shown. Age showed a weak positive correlation with the duration time of epilepsy ($r = 0.212$ at $p = 0.017$), and had a weak negative influence on three HRQoL dimensions (i.e., physical well-being, family relations and home life, school environment) (r: -0.278 and -0.261 at $p \leq 0.05$).

The duration time of epilepsy did not have a significant influence on HRQoL levels. Seizure frequency and duration time of epilepsy were in a medium weak correlation (r: 0.352, $p = 0.000$). Seizure frequency had a negative influence on four domains of HRQoL (physical and psychological well-being, friends, and social acceptance). Physical well-being was significantly influenced by several domains, mostly psychological well-being (r: 0.670 at $p \leq 0.001$) but was also influenced parent relations and home life, social support and peers and school environment. The same was seen for the psychological well-being variable.

Social acceptance was influenced negatively by more frequent seizures and positively by physical well-being and friends (r: -0.19-0.294 at $p \leq 0.05$). Moods and emotions, self-perception, autonomy and financial resources domains did not show significant correlations with the other variables and categories of HRQoL **(Table 4)**.

The mean scores showed a tendency to decrease with increasing seizure frequency. The mean scores of physical and psychological well-being domains fell exponentially with increasing frequency **(Figure 1)**.

HRQoL and antiepileptic drug treatment

The average treatment time was significantly longer for children receiving polytherapy compared to children with monotherapy (p: 0.001). The mean duration of epilepsy was

Table 4: Cross tabulation of age of epileptic patient. Duration of Epilepsy. Seizure frequency and six significant domains of KIDSCREEN Children and Adolescents test. The numbers of the columns and rows mark the same variable.

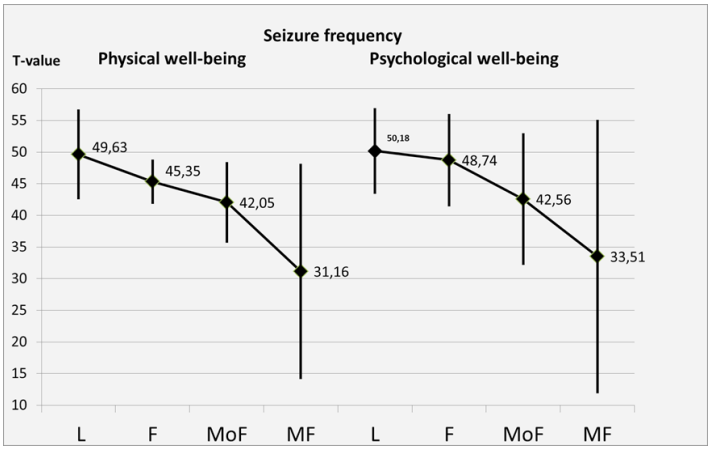
Variable		1	2	3	4	5	6	7	8	9
1. Age	r	1								
2. Time of E	r	0.212*	1							
3. Seizure frequency	r	0.185*	0.352**	1						
4. Physical well-being	r	-0.278**	-0.144	-0.275**	1					
5. Psychological well-being	r	-0.147	-0.067	-0.257**	0.670**	1				
6. Parent relations and home life	r	-0.261**	-0.013	-0.025	0.362**	0.428**	1			
7. Social support and peers	r	-0.116	-0.132	-0.271**	0.400**	0.430**	0.313**	1		
8. School environment	r	-0.213*	0.013	-0.080	0.431**	0.469**	0.500**	0.327**	1	
9. Social acceptance	r	0.054	-0.029	-0.192*	0.235**	0.182*	0.083	0.294**	0.198*	1

Abbreviations: *r*: Pearson correlation; *p*:*. Correlation is significant at the 0.05 level (2-tailed); **. Correlation is significant at the 0.01 level (2-tailed).' –' negative e correlation.

DOI: https://doi.org/10.30654/MJN.10017

3 years 9 months ± 32 months for monotherapy and 5 years 8.5 months ± 40 months for polytherapy. Ninety-one (63.2%) patients on monotherapy and 32 (22.2%) on polytherapy were seizure free or well-controlled regarding seizure frequency. Only 10 children had daily or weekly seizures.

Scores were significantly better with large ES (0.83) from the point of view of both children and parents in the group where children had to take only one kind of medicine. There was a significant difference in HRQoL depending on the type of drug therapy in the opinion of both children and parents at $p \leq 0.05$ **(Figure 2)**. Children undergoing polytherapy gave significantly lower scores than monotherapy patients, mainly for questions related to friendship: Have you had fun? Have you spent time with your friends? Have other girls and boys made fun of you? (*p*: 0.001-0.046).



Abbreviations: L-Least frequent. F-Less frequent. MoF-More frequent. MF-Most frequent.

Figure 1: Mean T-values and their standard deviations for children with epilepsy relating to seizure frequency and to the physical well-being and psychological well-being domains of the KIDSCREEN test.

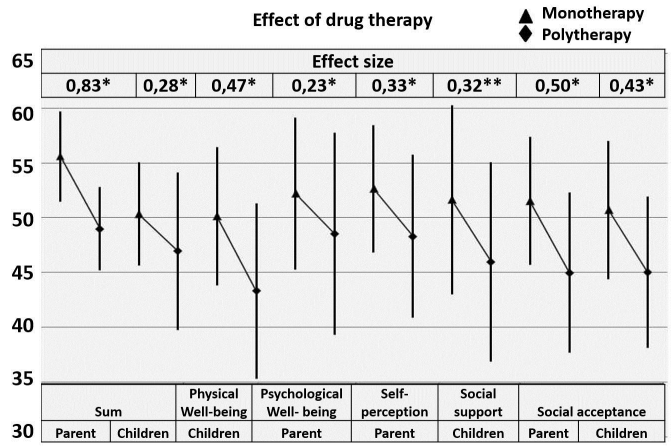


Figure 2: Drug therapy and quality of life: mean T-value scores of the significant domains of E children and parent proxy reports. Abbreviations: *p*:*. Correlation is significant at the 0.05 level (2-tailed); **. Correlation is significant at the 0.01 level. ES: Cohen's effect sizes.

Socio-demographic background

Among parents of E patients were 2.64 times more uneducated than among parents of GP, they had below or only elementary school level. One fifth of E parents were inactive worker (RR: 1.31). E children were frequently grown up in a nuclear family (RR: 2.61). Three times more of them were educated in special schools. In E population were more large family (RR: 4.6). E patients had more sick siblings and higher frequency of siblings with E **(Table 5).**

Table 5: Risk rates of different sociodemographic variables of children with Epilepsy-the data related to GP.

Category	E		GP		RR
	Nº	CI	Nº	CI	
Parents' Education					
≤ 8 class	18	0.14	12	0.05	2.64
Secundary Education	83	0.63	119	0.53	1.18
Highly Educated	31	0.23	95	0.42	0.54
Parents' Occupation					
Active	81	0.79	188	0.83	0.95
Inactive	21	0.21	36	0.16	1.31
Family Relationship					
Living Together/ Joint family	60	0.65	190	0.87	0.74
Single –Mosaic family	32	0.34	29	0.13	2.61
Type of School					
Normal level	104	0.82	206	0.93	0.88
Special or High level	23	0.18	14	0.06	3.0
Siblings					
None	32	0.23	103	0.56	0.41
1 sibling	56	0.41	65	0.36	1.13
2 or more siblings	49	0.35	14	0.076	4.6
Sibling with E	11	0.08	0	0	-
Sibling with allergy	3	0.02	23	0.09	0.22
Sibling with any illness	24	0.17	32	0.14	1.21

Abbreviations: Nº: Number of population. E: Epilepsy. GP: General population; CI: Cumulative incidence. RR: Risk ratio.

DISCUSSION

There are many HRQoL studies of children with epilepsy in the medical literature [1-26]. A recent study is one of a few available studies examining HRQoL self-reports of children with epilepsy and parent proxy-reports. [20-23,26-29,34,35]. As far as we know, there have been no similar HRQoL studies of epileptic children and adolescents in Hungary, and even for adults, only two surveys have been published [10,11].

The focus was directly on the views of children and adolescents, but valuable proxy data from parents were obtained as well.

DOI: https://doi.org/10.30654/MJN.10017

There is a need for HRQoL studies directly incorporating the views of patients, and we hope that this analysis can help determine more clearly the relationship between HRQoL and different variables of children and adolescents with E [1,35,36]. The data and results of our study were collected and analysed over a three-year period. We were fortunate to receive more questionnaires back than planned. The data of the general population were homogeneous enough to compare with the E group. While epilepsy is often associated with co-morbidities, the present study examined only those patients who were able to independently fill out the questionnaires; children with severe motor disabilities and/or severe intellectual impairments were not included in the study. We believe that this fact does not influence our results, since in this case the quality of life assessment was not influenced by a movement disorder or intellectual disability.

The essential aim of our study was to measure the quality of life of children with epilepsy using their own opinions. Our second basic aim was to investigate HRQoL of children not only from the point of view of children but from that of their parents as well. We attach great importance to the focus on opinions of different age groups, as the opinion of children and adolescents can vary considerably [5,6,9,26,34]. We also looked for the frequency of factors that impair the quality of life in the family environment.

Epilepsy has a negative impact on the HRQoL of children and adolescents with epilepsy. This was seen through comparisons with reports of children, adolescents and parental groups of the GP.

Newly diagnosed patients with E had the risk of low scores for HRQoL, according to the opinions of both children and their families [5], however, the HRQoL will almost certainly improve with treatment [12]. Several studies found similar results of a decreased HRQoL in the cases of new-onset, well-controlled, active or mixed E population [3-7,15,16].

The questions reflecting physical well-being are mainly connected to the movement of the child, and scores were significantly worse in our E groups compared to the control groups. This would be understandable in motor-disabled children but was not expected in the epileptic patients who had good motor function. Wu et al. [17] suggested that this may originate from the fear of injury during an epileptic seizure. We have frequently experienced that parents with E children are overprotective and needlessly protect their children from active movement, exercise and sports.

Psychological well-being, moods and emotions and self-perception differed from that of the general population. Some authors have found emotional and behavioural difficulties in E patients [5,17]. As mindfulness-based therapy significantly improved HRQoL in adult patients with drug resistant epilepsy [14], this method may be worth trying with children as well.

The school environment dimension received the lowest HRQoL scores among epileptic children and their parents. This can probably be explained by the anxiety and fear of a seizure occurring in school, in the sight of teachers and classmates; however, a study from Serbia concerning patients with children with well-controlled epilepsy had different findings, because physical functioning and school behaviour domains had the highest scores. They reported that intake of antiepileptic drugs in school and concern over seizure recurrence play a more important role in the HRQoL of epileptic children [18]. Similar to [17,28], we found that bullying (mainly in school) for being epileptic worsens social acceptance. The fact that parents' opinions were more positive than patients' scores for school and friends may be partial because parents have few opportunities to observe these situations. School performance was sign-poorer in Nigeria than healthy controls. It was predicted by psychosocial variables including psychopathology in both adolescents and their care takers; adolescents felt stigma, an attitude towards the illness and frustration of family functioning [28].

Differences and agreement between children and parent forms of HRQoL tests are always an issue, questioning whether proxy measuring is appropriate or not [8]. The parental and child reports showed good correlation in our study, as Chiancetti et al. found [26]. This means that a medium strong similarity was observed between the answers of the children and parents, but there were significant differences in another item. Parent-child agreement of mainly healthy children and adolescents tended to diminish with the increasing age of the child, as a large-scale Spanish longitudinal study showed [20]. It is well-known that parents of children with chronic diseases rate their children higher because they judge psychosocial functioning differently [34].

The dimension of parent relations and home life was the only one where no significant differences between diagnostic

groups and the general population were found. Family cohesion, which is reflected in the strength correlation of answers from children and adolescents and their parents, seems to be quite strong in the investigated samples.

In some previous studies, parents judged the HRQoL of their children to be lower than the child reported him/herself [21,22], however, Taylor et al. [5] found no differences. In this study, we observed significant differences between the responses of the children with E and their parents' answers in five domains (moods and emotions, self-perception, social support and peers, school environment, and social acceptance). These discrepancies showed that either the disease itself and/or other factors influenced the HRQoL. In contrast, maternal education and socio-demographic background did not affect the quality of life in a recent study, although the number of patients was low [19]. Parenting stress, low levels of epilepsy education and other effects might reduce family cohesion or child HRQoL [23].

No sex differences were found in the majority of HRQoL studies [5,17,18]. In other E studies, a negative feelings dimension and low adolescent female scores were observed [18,24]. Age-specific differences have been found in many publications [3,5-6,9,27,28,35], and age was identified as a very important variable in our study as well. Age had no predictive value in some other publications [6,7,22,25], but the number of patients was statistically low in some studies.

Our results have shown that higher seizure frequency caused a meaningful decrease in HRQoL for physical and psychological well-being and friendship. Not only were some parts of the self-reported HRQoL lower in an Iranian study, but the total score was lower as well [9]. Seizure-free years increase the HRQoL, but not linearly [21]. The severity of epilepsy usually worsens ratings of HRQoL in a large review [36]. Miller et al. found that the severity of seizures had no predictive value for a diminished HRQoL [16]. The frequency of seizures had a positive relationship with duration of E, so in our investigation a longer duration meant epilepsy that was more difficult to control. Duration of E did not influence full scores in spite of its effect on some of the elements of HRQoL [3,9], but a strong negative correlation with epilepsy duration was found in some other studies [8].

Miller et al. found that a higher number of medications limited the HRQoL of the E groups [6]. Our study revealed that patients treated with monotherapy had higher scores in the main psychological and environmental parts of HRQoL than patients on polytherapy. We think at least two factors could have influenced these facts. First, mainly children with well-controlled epilepsies were on monotherapy, and taking only one antiepileptic drug usually causes fewer side effects and is more convenient than taking several. Though many of our well-controlled epileptic patients were on polytherapy, this obviously caused more side effects, and environmental difficulties also played a role in their psychosocial attitudes.

Both parents and children with E have considered the worsening of their financial status more than the GP. E is a relatively expensive disease. Modern antiepileptic drugs are more expensive (but have fewer side effects) than the former. Although the cost of most anti-epileptic drugs is partially subsidized by National Health Insurance, they still mean an extra financial burden. Social support should improve the family budget, as Fayed et al. published [37,38]. Socio-demographic characteristics justify the disadvantage of parents and families caring for an epileptic child. Due to lower education, HRQoL is deteriorating, as reported in a large study [39]. The higher rate of inactivity in the labour market and the nuclear family was much higher (1.31, 2.61 times) in our patients with E. These can increase social concerns [40]. More often -4.6 times-come from families with multiple children. Among their brothers, epilepsy and other illnesses are more common. In a large family, financial difficulties occur more often. In other words, the reduced values in quality of life are also related to the socio-demographic background.

Limitations

This publication contains the self-reported opinion of children and parents. The main strength of our study is that it is based on the perspectives of children with E, not just the opinion of their parents. Because of the relatively wide age limit, we were able to compare the reports of children and adolescents. The strengths of our study are the inclusion of a relatively large patient group and a general population group. Applying the risk rate to analyze the sociodemographic background provides novel and surprising data.

The weaknesses were that this E population was not homogeneous in terms of epilepsy syndromes. Most of them had well-controlled E, so the HRQoL of patients with frequent seizures was not well represented. The results would

obviously be altered by including patients with daily seizures and motor or mental damage in our study, but this was not the aim, because it was important that children be able to fill in the questionnaire alone, giving their own opinion.

Based on our results, more scientific directions should be taken into consideration.

One type of epilepsy is significantly different from another type of epilepsy. There have even been important differences in useful medications for the treatment of epileptic syndromes. It is difficult to collect a larger number of patients with different epilepsy forms and taking different medications to gain deeper knowledge about our patients.

HRQoL had decreased exponentially with increasing seizure frequency in our population, but we had a few evaluable numbers of these epilepsy patients. Controversial articles have emerged from them with therapy resistant epilepsy. A HRQoL study with statistically larger population would have given to me more information.

CONCLUSION

Our results showed that our null hypothesis was not supported. Parent proxy reports were complementary to the children's reports in situations that are well-known for parents, e.g., physical and psychological states, but gave different scores for self-perception and school environment questions. The gap between self-reported and parent-reported HRQoL scores is well-known in chronic diseases.

The age, seizure frequency and drug therapy negatively correlated with each other and with many domains of HRQoL, primarily physical, psychological and environmental factors. The duration of E showed no influence on HRQoL. Epilepsy syndromes with a higher seizure frequency and longer durations need to be treated mainly with polytherapy. Well-managed E, with one or two drug therapies, was connected with higher HRQoL.

However, epilepsy is also a stigma in Hungary. Parents are not always aware of the emotional life and school environment of young people despite good family circumstances. Family background regarding the parent's occupation, education, marital status, large families was very disabled of children with epilepsy.

Socio-demographic characteristics justify the disadvantage of parents and families caring for an epileptic child. For patients receiving polytherapy and for ones with multiple seizures, monitoring of adverse reactions, family social and psychotherapeutic assistance is required.

Conflicts of Interest

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. There are no conflicts of interest. Authors have nothing to disclose.

Authors' Contributions

K.H. had the original idea. K.H., A.K., M.F. collected the data. Data entry was done by M.F., B.V. and A. K. The statistical analysis was carried out by M.F. and B.V. All authors contributed to data interpretation and writing the manuscript. All authors read and approved the final manuscript. A native English reviewer checked the grammar and the composition.

Acknowledgements

Authors would like to thank the participating families with epilepsy and healthy children. A big thank you goes to Antal Furedi for programming support. Jozsef Teglas helped with inputting data.

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DOI: https://doi.org/10.30654/MJN.10017