

The quality of life of children with epilepsy in Poland – the opinion of children and their parents

Dorota Talarska¹, Michał Michalak², Patrycja Talarska³

¹ Department of Preventive Medicine,
Karol Marcinkowski University of Medical Sciences, Poznań, Poland

² Department of Computer Science and Statistics,
Karol Marcinkowski University of Medical Sciences, Poznań, Poland

³ The Group of Secondary Schools no. 15, Poznań, Poland

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Correspondence

Dorota Talarska RN, PhD
Department of Preventive Medicine
11 Smoluchowskiego Str.
60-179 Poznań, Poland
Phone (48 61) 861 22 43
e-mail: pati.talarska@neostrada.pl

SUMMARY

Background. Every chronic illness, including epilepsy, has a negative effect on both the quality of life of the sufferer as well as on their relationship with their surroundings.

Aims. To investigate the quality of life of children suffering from epilepsy and analyse how they assessed and scored their experiences compared to their parents.

Materials and methods. The study included 209 children with epilepsy and their parents. The research tool was a questionnaire for gathering demographic and clinical data as well as the Pediatric Quality of Life Inventory™ 4.0 Generic Core Scales (PedsQL™ 4.0) questionnaire in two versions, one for 8–12 year olds and one for 13–18 year olds and their parents.

Results. Cronbach's alpha coefficient for the entire PedsQL™ 4.0 questionnaire was 0.91 and 0.93 for children with epilepsy and their parents respectively. Children rated their Total Scale Score higher (67.5 points) than their parents (62.5 points). Whilst analyzing children's functioning in different areas it was observed that girls' assessments were higher than boys', except for Emotional Functioning. Both parents and children scored School Functioning the lowest. The greatest agreement of responses was observed in the domain of Physical Functioning, the smallest in the domain of Emotional Functioning.

Conclusions. Quality of life was rated higher by both age groups of children suffering from epilepsy than by their parents. A statistically significant difference was found when comparing the assessment scores of children and parents in light of the following variables; child age, gender, illness duration, seizure frequency and treatment effectiveness.

Key words: epilepsy • child • parents • quality of life

INTRODUCTION

When planning the assessment of the functioning of children and adolescents suffering from epilepsy, should be considered: the history the disease, changes occurring in the period of adolescence as well as the level of social adaptation. A frequent problem for people with epilepsy are stereotypes connected with the course of the disease and the patients themselves. Such neg-

ative perception hinder social functioning for people with epilepsy (Ronen et al., 2003; Aydemir et al., 2011; Duan et al., 2012). Psycho-social development of a child requires constant interaction with peers as it teaches tolerance, practical partnership, can also be a triggering factor for new interests and shapes independence in young people. The lack of peer acceptance contributes

to low self-esteem (Mcewan et al., 2004). Apart from existing stereotypes, other reasons for social alienation are changes in the patient caused by the disease process as well as side effects caused by certain medicines like behavioral disturbances or learning difficulties (Ronen et al., 2003; Modi et al., 2011). As there are various aspects to be considered in the evaluation of the functioning of children, including the sense of satisfaction with one's level of functioning, measurements in this field are often made on the basis of scales of quality of life.

Questionnaires to assess quality of life in relation to health (Health Related Quality of Life – HRQL) include an analysis of the level of activity of an affected person in three key areas, derived from the WHO's definition of health, namely; physical, mental and social well-being (Ronen et al., 2003; Varni et al., 2003; Engelen et al., 2009; Gandhi et al., 2013; Ovšonková and Mahútová, 2014).

Some questionnaires used in similar research assume that their respondents will be parents answering on behalf of their children, providing information about their child's problems (Sabaz et al., 2003). As shown by studies conducted so far, some problems, especially emotional and/or social ones, are not perceived by parents at all or are interpreted differently (Ronen et al., 2003; Klatchoian et al., 2008; Talarska et al., 2011; Amiri et al., 2012). Consequently, studies involving both children and their parents are becoming more appreciated. Thanks to this approach, it is possible to evaluate the child's functioning from two different angles (Mcewan et al., 2004; Haneef et al., 2010). Parents is then the primary source of information about the disease process and complements information on the activity of the child if the child is too young or mentally incapacitated (Felder-Puig et al., 2004; Engelen et al., 2009; Haneef et al., 2010; Modi et al., 2011).

Depending on the purpose of the research, the chosen general or specific tools used should be modified for the specific group of patients in mind (Varni et al., 2001; Sabaz et al., 2003; Mcewan et al., 2004; Limbers et al., 2011).

The essence of the research on the quality of life of children and adolescents with chronic illnesses like epilepsy is usually a desire to know the impact of the disease and its treatment on patients' functioning. Researchers also aim to identify factors determining the assessment of children's quality of life as influenced by the course of the disease and the environment the patient functions in.

AIM

The aim of our study was to investigate the quality of life of children suffering from epilepsy and analyse how they assessed and scored their experiences compared to their parents.

MATERIALS AND METHODS

The study was conducted over a three year period and involved 209 patients with epilepsy, and their parents, from the Outpatient Clinic of the Department of Developmental Neurology at the University of Medical Sciences in Poznań.

The purpose of the study was explained in detail to participating children and parents prior to starting and they were familiarized with the questionnaires. Additionally, **written consent was required**. The study included children who had parental consent as well as those who expressed a willingness to participate in the study themselves. The research was carried out in the outpatient clinic once a week and involved children admitted on that specific day.

With the younger group of children the researcher read out the questions and wrote down the answers. Parents and children in the older group were also able to benefit from the researcher's help, if so required. Both the hospital management as well as the Head of Department gave their consent to carry out the research.

Ethics committee approved the subject of the study and the research tools.

Selection criteria:

- Participants to be children aged 8–18 years old and their parents;
- Consent from children and parents to participate in the study;
- Patients to be diagnostically confirmed with partial or generalized epilepsy;
- Participants to be receiving one of the following therapies: monotherapy, polytherapy, no medication;
- No presence of chronic comorbidities limiting the functioning of the patient;
- Normal or borderline normal level of IQ;
- A minimum 6 month history of epilepsy;
- Enrollment in compulsory education.

Among the variables included in the study were age: in accordance with the respective version (8–12 or 13–18 years old) of the PedsQL™ questionnaire; gen-

der, duration of illness (divided into the following subgroups; up to 1 year, 1–5 years, 6–10 years, over 10 years), type of seizures (simple partial, complex partial, primary and secondary generalized, unclassified), therapeutic effects, refractory epilepsy, seizure control; seizure frequency (daily – 1 a week, 1–2 times a month, 1–2 per 6 months, once a year, seizure-free for over 1 year) and method of treatment: monotherapy, polytherapy, no medication.

Research tools

An interview questionnaire for gathering demographic and clinical data and a Pediatric Quality of Life Inventory™ 4.0 Generic Core Scales (PedsQL™ 4.0) questionnaire in two versions, one for children aged 8–12 and one for 13–18 years old and their parents were used (Varni et al., 2001; Varni et al., 2003; Varni et al., 2006). The questionnaire contained 23 questions divided into the following areas of childrens' functioning: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), School Functioning (5 items). Answers corresponded to a 5-level Likert scale from 0 – signifying no problem to 4 – signifying almost always (Varni et al., 2001; Limbers et al., 2011; Amiri et al., 2012).

A respondent may receive from 0–100 points in both the childrens' and parents' version. Items are reverse scored and linearly transformed to a 0–100 scale as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0. The questionnaire took into account 2 scales used to summarize functioning: the Physical Health Summary Score covering the area of Physical Functioning and the Psychosocial Health Summary Score containing results from the remaining areas (Varni et al., 2001; Varni et al., 2003; Varni et al., 2006).

Prior to its use, the questionnaire was translated in accordance with the canons of a cultural adaptation tool. The reliability and validity of the results were assessed twice; at the preliminary and then at the final examination assessment of reliability was made using Cronbach's alpha coefficient. The coefficient for the whole PedsQL™ 4.0 questionnaire was 0.91 and 0.93 for children with epilepsy and their parents, respectively.

To verify the correct selection of specific questions in a given domain an interclass-correlation (ICC) was carried out. The ICC Total score was 0.89 for children with epilepsy and 0.92 in the parent proxy report version. Whilst in respect to specific areas the scores for children and their parents came to be 0.74 and 0.80 re-

spectively for Physical health and 0.87 and 0.90, respectively for Psychosocial health.

Statistical analysis

The reliability of the PedsQL™ 4.0 questionnaire was assessed with Cronbach's alpha coefficient describing internal consistency.

PedsQL™ 4.0 domain results were compared with the Mann-Whitney test. In the eventuality of more than two groups of data being compared the Kruskal-Wallis test was used and additionally Dunn's post hoc test was implemented to find homogenous groups. To compare quality of life assessments of the children and their parents the Wilcoxon test was performed. The interrater agreement (child vs parent) was measured with Cohen's kappa coefficient. A kappa coefficient value over 0.75 meant excellent, 0.40–0.75 fair to good and below 0.40 poor.

RESULTS

Characteristics of the study group

Within the group of children and adolescents with epilepsy the mean age was 13.03 ± 3.2 years and females prevailed numerically ($N=105$; 50.2%). In the group of 8–12 year olds there were 39 (43.8%) girls and 50 (56.2%) boys, while in the group aged 13–18 years old, 66 (55.0%) were girls and 54 (45.0%) were boys. The age of the parents ranged between 33–58 years old, the average age for women was 42.5 ± 6.2 and for men 45.7 ± 6.0 .

The mean duration of illness was 5.6 ± 3.5 , with the minimum length being 6 months and the maximum 17 years. Primary generalized seizures occurred in 106 (50.7%) patients, secondary generalized in 50 (23.9%), partial simple in 14 (6.7%), complex partial in 35 (16.8%) and unclassified in 4 (1.9%) children. Daily seizures occurred in 12 (5.7%) of the respondents, 1–4 times a month in 46 (22.0%), 1–2 times in 6 months in 43 (20.6%), once a year in 97 (46.4%) children. Eleven children were seizure-free for a period of one year (5.3%). Monotherapy was administered in the case of 141 (67.5%) children, polytherapy in 51 (24.4%) whilst 8.1% ($n=17$) of the group were medication-free. Children with refractory epilepsy constituted 27.7% ($n=58$) of the group.

To assess the functioning of children with epilepsy the PedsQL™ 4.0. questionnaire was used. The questionnaire was filled in by children and their parents. Results analysis was carried out in the following stag-

es. Firstly, it was examined whether there is a difference in the assessment of quality of life within two independent groups: namely between children and their parents. Then the difference in the assessment of the functioning as measured by children and their parents was analyzed. The last stage was a comparison of the compliance of responses in pairs between children and their parents.

Quality of Life as assessed by the group of children and the group of parents separately

In general, the group of children assessed their quality of life higher (67.5 points) as compared to their parents (62.5 points) (table 1). Girls rated both their Total Scale Score for quality of life slightly higher (68.1 points) than boys (66.8 points) as well as their functioning in all the specific domains except Emotional Functioning. Both girls as well as boys rated School Functioning the lowest out of all the categories. Similarly, parents assessed this domain the lowest too. In general, parents assessed boys higher, except for the School Functioning. Despite the observed differences in assessing quality of life as assessed by girls and boys and their parents, their statistical significance was not confirmed. Analyzing the two age groups: 8–12 and 13–18 years old, it was observed that both the group of children and the group of parents assessed the functioning of adolescents (13–18 years) higher. Only in the area of Emotional Functioning did the parents of younger children assess them higher. A statistically significant difference in the assessment of quality of life was confirmed by the group of children when analyzing age in all areas, except for Physical Health and Emotional Functioning. Older children rated their quality of life higher. In the group of parents, a statistically significant difference was only found when analyzing age as a variable in the assessment of functioning in the area of Social Functioning. Parents of older children assessed their functioning significantly higher.

Overall, quality of life of children with epilepsy, in relation to illness duration, was assessed best by children with disease duration less than 2 years, conversely it was rated the lowest when disease duration was over 10 years. Parents best assessed the functioning of children with a disease duration of 2–5 years, and worst with a duration period of over 10 years. A statistically significant difference was only found in the group of parents in their assessment of the Social Functioning of children.

The results of the group of children as compared to the parents

The Wilcoxon test was used to compare result scores of children and parents in all the various quality of life subgroups (table 2). A statistically significant difference at a level of <0.0001 was found in all domains of the PedsQL™ 4.0 questionnaire except Social Functioning ($p=0.0471$). A greater disparity was found when analyzing the following variables; age, gender and illness duration. The greatest compliance of results when considering all variables was observed in the Social Functioning domain. Statistically significant differences within this subgroup were only found between girls' assessment scores and those of their parents and between children suffering from the disease less than 1 year or 6–10 years and the results of their parents.

In general, the Total Test Score for the functioning of children showed a statistically significant difference between children's and parents' results when analyzing both age groups, gender as well as when illness duration was 1–5 years and 6–10 years.

A similarity of results between children and parents was seen in all domains of the questionnaire where the children were under 1 year of age (other than in Physical Health and Social Functioning) and in children over 10 years old.

The analysis of the clinical data regarding the disease additionally included: therapeutic effect, type of seizure, method of treatment and seizure frequency. Using the Mann-Whitney U test, a statistically significant difference between the assessments of the group of children and the group of parents with respect to the effect of treatment was shown both in the Total Scale Score ($p<0.001$) and in all areas of the questionnaire (children $p<0.001$, parents $p<0.001$).

Children with refractory epilepsy obtained lower scores in both children's and parents' assessments. At the same time, parents of children with refractory epilepsy scored their questionnaire much lower (Total Scale Score: refractory epilepsy; 48.5 points, seizure control; 5.3 points). Parents and children evaluated the area of School Functioning the lowest. Using the Kruskal-Wallis test a statistically significant difference was shown between the assessment of the quality of life as expressed by children and their parents in regards to the frequency of seizures (children and parents: Total Scale Score and all areas $p<0.05$).

Quality of life was rated the lowest by children who suffered from seizures once a month and every day

Table 1. The analysis of the functioning of children with epilepsy as evaluated by children and their parents

Subscales PedsQL™ 4.0	Gender		Age			Duration of disease					
	Girls	Boys	Mann-Whitney U Test	8–12 years	13–18 years	Mann-Whitney U Test	<1 year	1–5 years	6–10 years	>10 years	Kruskal-Wallis Test H3
Children points											
Physical Health	76.0 ± 20.3	75.7 ± 21.0	Z = 0.0551 p = 0.9560	72.7 ± 22.2	78.0 ± 19.3	Z = 1.5746 p = 0.1154	77.6 ± 18.1	76.3 ± 21.4	77.5 ± 18.4	64.3 ± 25.6	6.6548 p = 0.0838
Emotional Functioning	62.6 ± 20.7	66.2 ± 18.8	Z = 0.9530 p = 0.3406	62.4 ± 18.7	65.7 ± 20.5	Z = 1.5667 p = 0.1172	61.9 ± 18.2	65.8 ± 19.8	66.5 ± 18.5	55.7 ± 26.5	3.9729 p = 0.2644
Social Functioning	68.4 ± 25.1	66.0 ± 27.9	Z = 0.4205 p = 0.6741	60.9 ± 26.0	71.6 ± 26.1	Z = 2.8881 p = 0.0039	76.5 ± 24.2	69.9 ± 25.7	67.3 ± 26.6	54.4 ± 30.1	6.9934 p = 0.0721
School Functioning	59.7 ± 23.1	55.5 ± 20.6	Z = 1.3094 p = 0.1904	54.4 ± 20.4	60.0 ± 22.8	Z = 1.9669 p = 0.0492	59.2 ± 20.6	59.9 ± 21.6	56.3 ± 21.5	51.4 ± 28.1	2.4949 p = 0.4762
Psychosocial Health	63.6 ± 20.5	62.4 ± 19.1	Z = 0.5078 p = 0.6116	59.0 ± 19.0	65.7 ± 19.9	Z = 2.6400 p = 0.0083	65.9 ± 18.6	65.0 ± 19.8	63.5 ± 18.8	53.7 ± 25.1	4.2566 p = 0.2351
Total Score	68.1 ± 19.2	66.8 ± 18.4	Z = 0.6700 p = 0.5028	63.8 ± 18.9	70.0 ± 18.4	Z = 2.5656 p = 0.0130	70.0 ± 17.8	68.7 ± 19.2	68.3 ± 17.7	58.0 ± 22.8	4.8135 p = 0.1860
Parents											
Physical Health	68.3 ± 23.1	71.6 ± 21.4	Z = 0.8638 p = 0.3877	68.7 ± 22.7	70.8 ± 22.1	Z = 0.5823 p = 0.5604	71.1 ± 19.7	70.9 ± 22.6	71.4 ± 21.1	61.0 ± 26.0	3.6805 p = 0.2981
Emotional Functioning	56.7 ± 22.7	58.9 ± 18.4	Z = 0.4430 p = 0.6578	58.1 ± 20.9	57.5 ± 20.7	Z = 0.0343 p = 0.9726	59.2 ± 21.4	59.5 ± 22.5	58.9 ± 19.5	49.2 ± 20.1	4.3563 p = 0.2255
Social Functioning	63.8 ± 26.1	65.0 ± 28.0	Z = 0.3715 p = 0.7103	59.1 ± 25.4	68.1 ± 27.6	Z = 2.2903 p = 0.0220	68.8 ± 28.5	70.6 ± 27.0	60.9 ± 24.7	54.2 ± 30.4	7.9191 p = 0.0477
School Functioning	55.7 ± 24.1	50.3 ± 21.1	Z = 1.4243 p = 0.1544	50.4 ± 21.2	55.1 ± 23.9	Z = 1.4976 p = 0.1342	53.8 ± 22.4	56.1 ± 23.7	51.0 ± 20.9	47.0 ± 27.5	3.2158 p = 0.3595
Psychosocial Health	58.6 ± 21.6	58.1 ± 19.1	Z = 0.0333 p = 0.9735	55.7 ± 19.6	60.2 ± 20.9	Z = 1.6043 p = 0.1087	60.5 ± 22.0	62.0 ± 20.9	56.8 ± 18.8	50.2 ± 23.5	6.0706 p = 0.1082
Total Score	62.1 ± 21.1	62.9 ± 19.1	Z = 0.1542 p = 0.8775	60.2 ± 19.6	64.1 ± 20.4	Z = 1.5078 p = 0.1316	64.2 ± 20.9	65.3 ± 20.6	61.8 ± 18.7	53.8 ± 22.8	5.1649 p = 0.1601

a, b – groups followed by the same letter do not differ statistically significantly

Table 2. Summary of the analysis showing a statistically significant difference in the assessment of the functioning of children and adolescents with epilepsy when comparing children's and parents' questionnaire results

PedsQL™ Functioning	Age		Gender		Duration of disease			
	8–12 years	13–18 years	Girls	Boys	< 1 year	1–5 years	6–10 years	> 10 years
Physical Health	Ch 72.8±20.3	Ch 78.0±19.3	Ch 76.0±20.3	Ch 75.7±21.0	Ch 77.6±18.1	Ch 76.3±21.4	Ch 77.5±18.4	Ch 64.3±25.5
	P 68.7±22.7	P 70.8±22.1	P 68.4±23.1	P 71.6±21.4	P 71.1±19.7	P 70.9±22.6	P 71.4±21.1	P 61.0±26.0
	p=0.004	p=0.0001	p<0.0001	p=0.020	p=0.030	p=0.011	p=0.006	p=0.58
Emotional Functioning	Ch 62.4±18.7	Ch 65.7±19.3	Ch 62.6±20.7	Ch 66.2±18.1	Ch 61.9±18.2	Ch 65.8±19.8	Ch 66.5±18.5	Ch 55.7±26.5
	P 58.1±20.9	P 57.5±20.7	P 56.7±22.7	P 58.9±18.4	P 59.2±21.4	P 59.5±22.5	P 58.9±19.5	P 49.3±20.1
	p=0.10	p<0.0001	p=0.018	p=0.0002	p=0.59	p=0.008	p=0.009	p=0.10
Social Functioning	Ch 60.9±26.0	Ch 71.6±26.1	Ch 68.4±25.1	Ch 66.0±27.9	Ch 76.5±24.2	Ch 69.9±25.7	Ch 67.3±26.6	Ch 54.4±30.1
	P 59.1±25.4	P 68.1±27.6	P 63.8±26.1	P 65.0±28.0	P 68.8±28.5	P 70.6±27.0	P 60.9±24.7	P 54.2±30.4
	p=0.22	p=0.13	p=0.031	p=0.54	p=0.050	p=0.41	p=0.013	p=0.57
School Functioning	Ch 54.4±20.4	Ch 60.0±22.8	Ch 59.7±23.1	Ch 55.5±20.6	Ch 59.2±20.6	Ch 59.9±21.6	Ch 56.3±21.5	Ch 51.4±28.1
	P 50.4±21.2	P 55.1±23.9	P 55.7±24.1	P 50.3±21.1	P 53.8±22.4	P 56.1±23.7	P 51.0±20.9	P 47.0±27.5
	p=0.001	p=0.003	p=0.010	p=0.0006	p=0.14	p=0.019	p=0.015	p=0.16
Psychosocial Health	Ch 59.0±19.0	Ch 65.7±19.9	Ch 63.6±20.5	Ch 62.4±19.1	Ch 65.9±18.6	Ch 65.0±19.8	Ch 63.5±18.8	Ch 53.7±25.1
	P 55.7±19.6	P 60.2±20.9	P 58.6±21.6	P 58.1±19.1	P 60.5±22.0	P 62.0±20.9	P 56.8±18.8	P 50.2±23.5
	p=0.004	p=0.0002	p=0.001	p=0.0007	p=0.20	p=0.11	p=0.0002	p=0.08
Total Score	Ch 63.8±18.9	Ch 69.9±18.4	Ch 68.1±19.2	Ch 66.8±18.4	Ch 70.0±17.8	Ch 68.7±19.2	Ch 68.3±17.7	Ch 58.0±22.8
	P 60.2±19.6	P 64.1±20.4	P 62.1±21.1	P 62.9±19.1	P 64.2±20.9	P 65.3±20.6	P 61.8±18.7	P 53.8±22.8
	p=0.0003	p=0.0000	p<0.0001	p=0.0002	p=0.09	p=0.022	p=0.0001	p=0.10

Ch – children, P – parents

(Scale Total Score 53.9 points) and by the parents of children who suffered seizures once a month (Total Scale Score 47.0 points). No statistically significant difference was demonstrated by the Kruskal-Wallis test in terms of quality of life assessment between children and parents taking into account the type of seizure, neither in Scale Total Score ($p>0.05$), nor in individual domains ($p>0.05$). The Mann-Whitney U test indicated no difference in quality of life of children undergoing monotherapy or polytherapy in regards to the Total Scale Score nor in specific areas of the PedsQL™ 4.0 questionnaire ($p>0.05$) between the groups of children and parents.

The group of children compared to the group of parents

Cohen's kappa coefficient of agreement between the responses of children and their parents was between 47.2%–79.6%. The greatest agreement of responses was observed in the area of Physical Functioning (on average 64.5%), the lowest in the area of Emotional Functioning (52.94%). The lowest compliance was observed in answer to questions regarding feelings of fear (47.24%), worrying (48.5%) as well as apprehension that the child will not keep up with his/her peers (48.24%).

DISCUSSION

Studies relating to the quality of life of patients with epilepsy enrich the information available on the impact of the disease and its treatment on the functioning of children (Ronen et al., 2003; Sabaz et al., 2003; Ovšonková and Mahútová, 2014). Previous clinical evaluations focused primarily on the analysis of seizures and the cognitive functioning of children. Recently, it has become more common to look at the subject more holistically, in particular considering the physical, emotional and social functioning of children as well as their involvement in school when assessing the effectiveness of treatment (Varni et al., 2001; Haneef et al., 2010; Modi et al., 2011; Gandhi et al., 2013).

The PedsQL™ 4.0 Generic Core Scales questionnaire is a proven methodological tool used in the assessment of the quality of life of children and adolescents with various illnesses. Due to a lack of a version of the questionnaire specifically tailored towards children with epilepsy, the PedsQL™ 4.0 general Generic Core Scales version was used.

In previous research examining the reliability and internal consistency of the questionnaire, Cronbach's alpha co-efficient lay most commonly at $\alpha=0.84$ – 0.90 for both the children's version of the questionnaire and

the parent's version (Varni et al., 2001; Engelen et al., 2009; Limbers et al., 2011; Amiri et al., 2012). Within this study, Cronbach's alpha was slightly higher for both children and adults (0.91–0.93). Furthermore, inter-class-correlation (ICC) confirmed a strong consistency and accuracy of questions in their respective domains.

Among the variables affecting the assessment of the quality of life of children with epilepsy, researchers most often mentioned factors such as age, type of epilepsy, frequency of seizures and medicinal side effects (Ronen et al., 2003; Varni et al., 2003; Haneef et al., 2010; Aggarwal et al., 2011). Within this study, statistically significant differences were observed when comparing children's assessment of quality of life with that of their parents when analyzing frequency of seizures and the effect of treatment. Similarly, statistically significant differences were also found when looking at age, gender and illness duration between 1–10 years. Other researchers have pointed out that the assessment results of parents can be influenced by their level of education and socio-economic situation (Varni et al., 2006; Engelen et al., 2009; Aggarwal et al., 2011). Studies to date have shown that children, with epilepsy that is under control, rate their quality of life higher than children with refractory epilepsy (Haneef et al., 2010; Talaraska et al., 2011). However, their assessment is lower than that of healthy children or those who are chronically ill (Haneef et al., 2010; Modi et al., 2011; Wirasuti et al., 2011; Gandhi et al., 2013). Results from both this study and from those of different authors indicate that girls assess both their overall quality of life (Total Scale Score), as well as their functioning in all specific areas (except for Emotional Functioning) higher than boys (Amiri et al., 2012).

Within this study, parents assessed boys slightly higher than girls, other than in the domain of School Functioning. In the study by Amiri et al. (2012) on healthy and chronically ill children, parents assessed the functioning of girls higher than boys, except in the Emotional Functioning domain.

Reinfjell et al. (2006) also drew attention to the lower scores for girls in the Emotional Functioning domain among a group of healthy children in their research. In contrast, gender was not statistically significant in the assessment of quality of life by children and parents in a study by Varni et al. (2003) involving healthy and chronically ill children.

Analyzing age as a variable and looking in particular at the 8–12 year old and 13–18 year old categories,

both this study and Varni et al. (2003, 2006) show that older children scored higher in their assessment score (other than in the domain of Emotional Functioning), both in their self assessment and that of their parents. In comparison, Engelen et al. (2009) obtained results where the lowest Total Scale Score (77.09) was obtained by a group of chronically ill children in the 13–18 years old age category. In contrast, a group of healthy children aged 13–18 assessed their Total Scale Score higher than younger healthy and chronically children as well as chronically ill children of the same age. In both age groups chronically ill children assessed School Functioning the lowest (Engelen et al., 2009).

Within this study, parents rated the quality of life of their children lower than their children did in general and but also when analyzing the variables age, gender and illness duration. Both children and parents evaluated the domain of School Functioning the lowest. Similar results were obtained by other authors (Varni et al., 2001; Varni et al., 2006; Haneef et al., 2010; Duan et al., 2012; Gandhi et al., 2013).

In a study by Haneef et al. (2010) involving children with epilepsy, healthy children and children suffering from other chronic diseases, the lowest Total Scale Score was attained by children with epilepsy and their parents. School Functioning was rated the lowest by children whilst parents rated School Functioning and Emotional Functioning the lowest (Haneef et al., 2010). Incidentally, Social Functioning and School Functioning were the domains assessed the lowest by parents in a study conducted on the basis of a German version of the PedsQL™ 4.0 questionnaire whilst Social Functioning was rated the lowest by children (Felder-Puig et al., 2004).

Similarly in this study, School Functioning was one of the areas assessed the lowest by both parents and children. In a study by Aldenkamp et al. (2003) learning problems occurred in 1/3 of the group. It was found that frequent seizures with short relapse periods had an impact on physical activity, memory and cognitive processes. Girls fared slightly better in terms of language, cognition, social activity and behavior (Aggarwal et al., 2011).

Among the factors affecting quality of life, illness duration was mentioned. Reducing the number of seizures and the adverse side effects of medication contributes to improving the quality of life of children (Modi et al., 2011; Talaraska et al., 2011). New medications have a more positive effect on cognitive functions. A nega-

tive correlation was observed between the number of medications taken by a patient and memory (Sabaz et al., 2003; Mcewan et al., 2004).

The way children perceive themselves and their disease is important for building self-esteem and satisfaction with their level of functioning as it determines their assessment of the quality of life (Ovšonková and Mahútová, 2014).

Within this research paper an average agreement of responses was found between parents and children. In the case of Emotional Functioning it was low. These observations should be taken into consideration when assessing the effectiveness of treatment and possible recommendations. Similar results were also obtained by other researchers (Felder-Puig et al., 2004; Reinfjell et al., 2006). Klatchoian et al. (2008) attained results which pointed to a lower level of agreement in the assessment between parents and children in reference to Social and Emotional Functioning. Amiri et al. (2012) showed a medium level of response agreement between parents and children, with Social Functioning exhibiting the lowest degree of compliance.

The study of quality of life helps to understand the impact of the disease on children's functioning in different areas and to identify the areas posing the greatest difficulty. Such an approach, similar to the principles of holistic care planning, allows for the provision of proper support for children and adolescents. The need for this kind of care is compounded by this study and others which clearly show the prevalence of problems in School and Emotional Functioning. These problems may be due to the specific developmental age of a child, but could also be affected by adverse drug reactions. The results clearly call for the cooperation of specialists from various fields. The discrepancies between the children's perceptions of their illness and that of their parents may arise from among other things; different expectations and a lack of knowledge in parents about the disease and/or their child's feelings. Consequently, the obtained results should be taken into consideration not only when collecting information about the child but also when assessing the effectiveness of his/her treatment. A meaningful and accurate assessment of quality of life should be based on an analysis of the functioning of the child including the opinions of the child, his/her parents as well as those of other specialist e.g. a pediatrician or a psychologist.

CONCLUSIONS

1. Quality of life was rated higher by both age groups of children suffering from epilepsy than by their parents.
2. The greatest results compliance between children and parents was seen in Physical Functioning and the least in Emotional Functioning.
3. A statistically significant difference was found when comparing the assessment scores of children and parents in light of the following variables; child age, gender, illness duration, seizure frequency and treatment effectiveness.

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CONFLICT OF INTEREST DISCLOSURE

We confirm that there are no conflicts of interest to disclose.

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