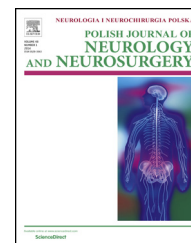


Available online at www.sciencedirect.com

ScienceDirect

journal homepage: <http://www.elsevier.com/locate/pjnns>

Original research article

Children with epilepsy against their healthy peers and those with headaches: Differences–similarities



Dorota Talarska^{a,*}, Michał Michalak^b, Patrycja Talarska^c,
Barbara Steinborn^d

^a Department of Preventive Medicine, Poznan University of Medical Sciences, Poznań, Poland

^b Department of Computer Science and Statistics, University of Medical Sciences, Poznań, Poland

^c PhD student at University of Medical Sciences, Poznań, Poland

^d Developmental Neurology Clinic, University of Medical Sciences, Poznań, Poland

ARTICLE INFO

Article history:

Received 5 January 2017

Accepted 18 October 2017

Available online 27 October 2017

Keywords:

Children

Epilepsy

Life quality

Peers

ABSTRACT

Introduction: Epilepsy, like most chronic diseases, affects bio-psycho-social functioning of children and adolescents.

The aim of this work was to assess functioning of children with epilepsy compared with the group of healthy children and those with headaches carried out by children themselves and their mothers.

Material and methods: The study included 209 children with epilepsy and 173 children with headaches and 182 healthy students and their mothers. The research tool was Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL™ 4.0) questionnaire.

Results: Quality of life of healthy children was rated the highest in all areas by both children and mothers. In younger and older children, difference was demonstrated between the assessment of the quality of life of healthy children and the ones with epilepsy or healthy children and the ones with and headaches in all areas of the PedsQL™ 4.0 questionnaire ($p < 0.05$). Children with epilepsy had the most difficulties in subscale School Functioning in their own and their mothers' opinion. Healthy children and their mothers rated the subscale Emotional Functioning lowest.

Conclusions: The functioning of children with epilepsy in the assessment of children and their mothers was the closest to the functioning of children with headaches. Quality of children's life assessment by children with epilepsy and by healthy children differed between the group of girls and boys and between older and younger children in all PedsQL™ 4.0 questionnaire areas. A medium response compatibility between children with epilepsy and their mothers was shown in individual questions.

© 2017 Published by Elsevier Sp. z o.o. on behalf of Polish Neurological Society.

* Corresponding author at: Department of Preventive Medicine, Poznan University of Medical Sciences, 6 Świącickiego Str., 60-781 Poznań, Poland.

E-mail address: pati.talarska@neostrada.pl (D. Talarska).

<https://doi.org/10.1016/j.pjnns.2017.10.008>

0028-3843/© 2017 Published by Elsevier Sp. z o.o. on behalf of Polish Neurological Society.

1. Introduction

Authors of earlier studies on the evaluation of the quality of life of chronically ill people pointed out that it is important not only to take into account the functional limitations and intensity of symptoms, but also according to the initiative of WHO, analyze human functioning in all main areas of activity [1-6]. This approach contributed to the creation of tools evaluating quality of life as satisfaction with the functioning in biological, social and psychological domains [2,7-9]. In addition, it is important to objectify the evaluation while maintaining its subjective dimension. For this purpose some authors suggest a necessity of comparing the evaluation made by the patients with others, e.g. the researcher or guardian. If the study takes into account the comments of others, one should remember that each person makes the assessment from their own perspective and refers to the knowledge and experience that not always reflect the real needs of a patient [1,7,8,10,11].

Psychosocial dimension is often emphasized by people who are ill or incapacitated as the most important in evaluating the quality of life. Children with epilepsy, as well as with other chronic diseases, shape the perception of themselves and their quality of life on the basis of relationships with others. The frequency of seizures, mental functioning and mood significantly affect the image of the child and his/her social contacts [2,8,12-14]. Children with frequent seizures, reduced IQ and learning disabilities experience lower acceptance in the group of peers. Many children with epilepsy feel the stigma of the disease [15-19]. Formation of self-esteem depends also on the attitudes of parents. Children who do not have acceptance from the immediate family assess their quality of life as low. Depression and parents' anxiety, low economic status and ignorance about the disease are also mentioned as factors affecting the quality of life of children with epilepsy [13,18,19]. Lack of knowledge about epilepsy, resulting in shame and overprotection, makes parents limit child's contacts with their peers. Improper attitudes toward children are most often manifested as excessive control during meetings with peers, performing tasks instead of the child and releasing them from basic household duties [20]. The more barriers the child feels, the worse he/she assesses their situation [16,17]. Fear of being rejected by the environment causes that the patients, as well as their relatives, do not inform friends and teachers about the child's condition. Lack of information increases the risk of not providing appropriate assistance and of exposure to factors triggering seizures.

Quality of life for children with epilepsy, as well as healthy ones or ones with other chronic disease, depends on many interrelated factors. Therefore, when planning the provision of appropriate support, an assessment of the quality of life must be systematically performed, including not only information about the effects of treatment but also psycho-social functioning, which gives a more complete picture of the course of a disease.

The aim of the study was to assess the functioning of children with epilepsy against the peer group of healthy children and children with headaches and also to compare the

assessment of children with the one performed by their mothers.

2. Material and methods

During the 3-year period, the study included 209 children with epilepsy from the Outpatient Clinic of Developmental Neurology at The Poznań University of Medical Sciences and their mothers. The control group consisted of 173 children with headaches, also from the clinic, and 182 students from schools: Elementary, Middle and High School in Poznań with their mothers.

2.1. The course of study

The studies in Outpatient Clinic were conducted once a week and included children with epilepsy and headaches who had an appointment with a neurologist on a given day. In the group of younger children, the questions were read and answers written down by the researcher. In case of any doubt, parents and children could ask the researcher for help. Due to the small participation of fathers in the study ($n = 15$), only questionnaires completed by mothers were included in further analysis. The purpose of testing was accurately explained and children and parents were familiarized with questionnaires immediately before the test.

Further studies were carried out in schools with two age groups: 8-12 and 13-18 years old. One class from each age group was randomly selected. In the group of 8-12 years old, a total of 50% of parents and/or children (all chronically ill or physically incapacitated children were excluded) resigned from the study, and 20% resigned in the group of 13-18 years old. The study took place during organized meetings between teachers and parents, during which the nature of research was discussed, and then, the questionnaires were distributed.

Children filled questionnaires during lessons given by the class teacher. The study included only those children who, as well as their parents, agreed to participate in the study and returned completed surveys.

Both parents and children could resign from completing the questionnaires during the study. In the whole group, despite prior consent, 2 parents and 3 children resigned in the process of completing surveys.

The management of the hospital and schools agreed to participate in the study. The ethical committee accepted the topic and research tools.

2.2. The selection criteria for children

- Children aged 8-18 years and their parents,
- No other chronic comorbidities significantly affecting health,
- IQ within or on the border of standards,
- Learning in school.

Additional selection criteria for children with headaches and epilepsy:

- Diagnostically confirmed Epilepsy (ILAE) and headache (IHS-2004),
- Duration of disease – more than 6 months from diagnosis.

2.3. Research tool

Interview questionnaire for gathering demographic and clinical data was used along with Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL™ 4.0) version for children 8–12 and 13–18 years old and their parents [5,7,10,11,21].

The questionnaire contains 23 questions divided into the following: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), School Functioning (5 items). The questionnaire takes into account the two summarized functional areas: Physical Health Summary Score covering the area of Physical Functioning and Psychosocial Health Summary Score containing scores from the other areas.

The sum of these areas is the overall quality of life (Total Score). The answers refer to a 5-level Likert scale from 0 – no problem to 4 – almost always [5,7,21]. In result, the respondent may receive 0–100 points in both children and parents version.

Before using the tool, cultural adaptation was performed. To evaluate the reliability of the PedsQL™ 4.0 questionnaire, α -Cronbach's coefficient was used. All groups showed α -Cronbach's coefficient in the range 0.84–0.93. It was lowest in a study of healthy children and their parents (Table 1).

To verify the correct selection of specific questions to an individual area, the interclass-correlation (ICC) was used. ICC for the whole questionnaire in healthy children amounted to 0.89, in children with headaches to 0.83, with epilepsy to 0.89. In the version of the parent proxy-report ICC was: in parents of healthy children 0.80, with headaches 0.87 and with epilepsy 0.92.

2.4. Statistical analysis

The reliability of PedsQL™ 4.0 questionnaire was assessed by Cronbach's alpha coefficient describing internal consistency. Since data did not follow distribution, we used the Mann-Whitney test in the analysis.

PedsQL™ 4.0 domains results were compared with Mann-Whitney test. If data were compared between more than two groups, Kruskal Wallis test was used and, additionally, post hoc Dunn's test to find homogenous groups. To compare quality of life measures between children and their parents

Wilcoxon Test was performed. The interrater agreement (child vs mother) was measured by Cohen's kappa coefficient.

3. Results

3.1. Characteristics of the study group

3.1.1. Children with epilepsy

In the group of children and adolescents with epilepsy, the mean age was 13.03 ± 3.2 years. In the group aged 8–12, there were 39 (43.8%) girls and 50 (56.2%) boys, while in the age group of 13–18, there were 66 (55.0%) girls and 54 (45.0%) boys. The mean age of mothers was 42.5 ± 6.2 years.

The mean duration of the disease was 5.6 ± 3.5 years, at least 6 months, maximum 17 years. Children with refractory epilepsy accounted for 27.7% ($n = 58$) of the group. 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%), 1 a year in 97 (46.4%) children. There were 11 (5.3%) children without a seizure during the year. Monotherapy was applied in 141 (67.5%) children including 43 (30.5%) on carbamazepine treatment (CBZ), 81 (57.4%) on Valproic acid treatment (VPA), 17 (12.1%) treated with new antiepileptic drug. Polytherapy was applied in 51 (24.4%) children, no drug therapy concerned 8.1% ($n = 17$) of the group.

3.1.2. Children with headaches

In the group of children with headaches girls accounted for 59% ($n = 102$), the mean age was 15.04 ± 2.9 years. There were 15 (45.4%) girls and 18 (54.6%) boys in the 8–12 age group, while in the 13–18 age group there were 87 (62.1%) girls and 53 (37.9%) boys. Children with migraine constituted 40.5% ($n = 70$), of which 41.4% suffered migraines with an aura and 59.5% ($n = 103$) with tension headache. Chronic headaches occurred in 110 (63.6%) children, including daily headaches in 17.1% ($n = 31$). The mean age of mothers was 43.3 ± 5.7 years.

3.1.3. Healthy children

The girls constituted 58.2% ($n = 106$) of the group. The mean age was 14.43 ± 2.9 years. There were 26 (60.5%) girls and 17 (39.5%) boys aged 8–12 years, and respectively, 83 (59.7%) and 56 (40.3%) aged 13–18 years. The mean age of mothers was 43.3 ± 4.7 years.

Table 1 – Summary of Cronbach's alpha coefficient PedsQL™ 4.0 in each group.

PedsQL™ 4.0 Functioning subscales	Epilepsy		Healthy		Headache	
	Cronbach's alpha		Cronbach's alpha		Cronbach's alpha	
	Children	Parents	Children	Parents	Children	Parents
Physical	0.77	0.83	0.73	0.89	0.86	0.86
Emotional	0.67	0.75	0.77	0.77	0.74	0.69
Social	0.85	0.88	0.66	0.63	0.78	0.84
School	0.78	0.84	0.68	0.69	0.82	0.76
Psychosocial	0.89	0.91	0.81	0.77	0.87	0.85
Total Score	0.91	0.93	0.85	0.84	0.92	0.91

3.2. Evaluation of the quality of life of children – a comparison of study groups

Analyzing the assessment of the quality of life of children separately in the group of children and mothers, it was found that the functioning in specific areas and Total Scores was rated the lowest in children with epilepsy, followed by children with headaches. Healthy children were assessed the highest in all areas, both in self-report and parent proxy-report. In the group of children as well as parents, there was a difference ($p < 0.05$) in the assessment of the functioning between children with epilepsy and healthy ones, and between healthy children and children with headaches, in specific areas as well as in Total Score.

Whereas smaller differences were demonstrated in the evaluation of children with epilepsy and headaches, especially in the Subscales Emotional Functioning and Physical Functioning. The area with the lowest score in the group of children with epilepsy and their mothers was School Functioning, while in the group of healthy children and with headaches, it was Emotional Functioning. Children with headaches also marked the lowest score in School Functioning. While analyzing the results of studies, it was examined whether there is a difference in the assessment of children's functioning formulated by children and mothers depending on basic

variables. Taking into account the specificities of the three analyzed groups of healthy children, children with epilepsy and children with headaches, two common variables were distinguished: age and gender.

3.3. The quality of life of children regarding the child's gender

3.3.1. Comparison of the assessment of quality of life of girls and boys in following groups: healthy children, children with epilepsy, children with headaches.

In the group of children with epilepsy the girls assessed their overall quality of life (Total Score) higher than boys (Tables 2 and 3), in the other two groups Total Score was higher in boys. Mothers assessed higher the total quality of life for boys in the groups of children with epilepsy and children with headaches, and for girls in the group of healthy children. Boys in all groups and girls with epilepsy gave the lowest score to School Functioning. Healthy girls and ones with headaches gave the lowest score to Emotional Functioning.

Mothers of girls and boys with epilepsy and boys with headaches gave the lowest score to children's functioning in the area of School Functioning, while in the remaining groups, they indicated Emotional Functioning.

Table 2 – Assessment of functioning with reference to child's gender – children.

PedsQL 4.0 Subscales Children	1. Children with epilepsy		2. Healthy children		3. Children with headaches		ANOVA Kruskal-Wallis test H2
	Mean		Mean		Mean		
	G ^a N-106	B N-103	G N-106	B N-76	G N-102	B N-71	
Physical Functioning Hoc hoc	76.0 G: 1:2 $p = 0.0013$ B: 1:2 $p = 0.0000$	75.7	85.7 1:3 $p = 0.0053$ 1:3 $p = 1.0000$	89.1	68.1 2:3 $p = 0.0000$ 2:3 $p = 0.0001$	77.2	G: 45.0381 $p = 0.0000$ B: 24.5483 $p = 0.0000$
Emotional Functioning Hoc hoc	62.6 G: 1:2 $p = 0.0460$ B: 1:2 $p = 0.0000$	66.2	70.0 1:3 $p = 0.1869$ 1:3 $p = 1.0000$	79.5	57.8 2:3 $p = 0.0000$ 2:3 $p = 0.0013$	68.5	G: 19.0544 $p = 0.0001$ B: 23.4733 $p = 0.0000$
Social Functioning Hoc hoc	68.4 G: 1:2 $p = 0.0000$ B: 1:2 $p = 0.0000$	66.0	88.7 1:3 $p = 0.0004$ 1:3 $p = 0.0067$	89.1	82.1 2:3 $p = 0.0458$ 2:3 $p = 0.1796$	81.3	G: 39.9486 $p = 0.0000$ B: 28.0768 $p = 0.0000$
School Functioning Hoc hoc	59.7 G: 1:2 $p = 0.0000$ B: 1:2 $p = 0.0000$	55.5	78.9 1:3 $p = 0.7706$ 1:3 $p = 0.5277$	79.0	63.7 2:3 $p = 0.0000$ 2:3 $p = 0.0000$	59.3	G: 43.7480 $p = 0.0000$ B: 54.7846 $p = 0.0000$
Psychosocial Health Hoc hoc	63.6 G: 1:2 $p = 0.0000$ B: 1:2 $p = 0.0000$	62.4	79.2 1:3 $p = 0.7635$ 1:3 $p = 0.0774$	82.5	67.6 2:3 $p = 0.0050$ 2:3 $p = 0.0000$	69.6	G: 39.8068 $p = 0.0000$ B: 53.2429 $p = 0.0000$
Total Score Hoc hoc	68.1 G: 1:2 $p = 0.0000$ B: 1:2 $p = 0.0000$	66.8	81.4 1:3 $p = 0.0001$ 1:3 $p = 0.1442$	84.8	67.8 2:3 $p = 0.0000$ 2:3 $p = 0.0000$	72.6	G: 44.0181 $p = 0.0181$ B: 51.6793 $p = 0.0000$

^a G – girls, B – boys.

Table 3 – Differences in assessment of functioning of children with reference to gender – mothers.

PedsQL™ 4.0 Subscales	1. Children with epilepsy		2. Healthy children		3. Children with headache		ANOVA Kruskal-Wallis test
	Mean		Mean		Mean		
	G ^a N-106	B N-103	G N-102	B N-75	G N-102	B N-70	H2
Physical Functioning Hoc hok	68.4 G: 1:2 $p = 0.0000$ B: 1:2 $p = 0.0022$	71.6	82.3 1:3 $p = 0.8938$ 1:3 $p = 1.0000$	80.7	66.1 2:3 $p = 0.0000$ 2:3 $p = 0.0316$	75.0	G: 37.0650 $p = 0.0000$ B: 12.2876 $p = 0.0021$
Emotional Functioning Hoc hok	56.7 G: 1:2 $p = 0.0054$ B: 1:2 $p = 0.0000$	58.9	66.2 1:3 $p = 1.0000$ 1:3 $p = 0.9983$	71.1	58.8 2:3 $p = 0.0407$ 2:3 $p = 0.0037$	61.4	G: 10.8469 $p = 0.0044$ B: 21.3274 $p = 0.0000$
Social Functioning Hoc hok	63.8 G: 1:2 $p = 0.0252$ B: 1:2 $p = 0.5300$	65.0	75.1 1:3 $p = 0.0000$ 1:3 $p = 0.0006$	74.3	80.8 2:3 $p = 0.0600$ 2:3 $p = 0.0715$	80.2	G: 25.2631 $p = 0.0000$ B: 14.1986 $p = 0.0008$
School Functioning Hoc hok	55.7 G: 1:2 $p = 0.0000$ B: 1:2 $p = 0.0000$	50.3	77.6 1:3 $p = 0.0806$ 1:3 $p = 0.1842$	73.4	63.5 2:3 $p = 0.0000$ 2:3 $p = 0.0000$	57.2	G: 50.0346 $p = 0.0000$ B: 51.9885 $p = 0.0000$
Psychosocial Health Hoc hok	58.6 G: 1:2 $p = 0.0000$ B: 1:2 $p = 0.0000$	58.1	73.0 1:3 $p = 0.0065$ 1:3 $p = 0.0154$	72.9	67.4 2:3 $p = 0.1326$ 2:3 $p = 0.0707$	66.3	G: 25.9223 $p = 0.0000$ B: 28.5230 $p = 0.0000$
Total Score Hoc hok	62.1 G: 1:2 $p = 0.0000$ B: 1:2 $p = 0.0000$	62.9	76.1 1:3 $p = 0.4626$ 1:3 $p = 0.8928$	75.6	66.9 2:3 $p = 0.0005$ 2:3 $p = 0.1050$	69.3	G: 28.3773 $p = 0.0000$ B: 20.5301 $p = 0.0000$

^a G – girls, B – boys.

3.3.2. Comparison of the assessment of quality of life of girls with epilepsy with their healthy peers and with girls with headaches and boys with epilepsy with their healthy peers and boys with headaches

The statistical analysis in the group of children and mothers (Tables 2 and 3) showed a difference ($p < 0.05$) in the assessment of functioning of healthy girls, girls with epilepsy, and girls with headaches as well as boys in these groups, in all areas of the PedsQL™ 4.0 questionnaire, and in Total Scores. Accurate statistical analysis (Hoc hok) confirmed the difference in the assessment of quality of life in individual areas and in Total Scores between: girls with epilepsy and healthy peers, boys with epilepsy and healthy boys, and healthy girls and girls with headaches, as well as healthy boys and boys with headaches (except Social Functioning in boys). Taking into account children with epilepsy and headaches, a difference was demonstrated only in the subscale Social Functioning in the group of boys. Girls differed in the assessment of their functioning in the areas Physical Functioning, Social Functioning, and Total Score.

In the group of mothers, Hoc hok analysis showed a difference in the assessment of functioning between: girls with epilepsy and healthy peers and boys with epilepsy and healthy boys in all areas (except Social Functioning in boys) and Total Score. A difference was demonstrated only for assessment of children's functioning in the area of Social Functioning and Psychosocial Health between mothers of girls with epilepsy and headaches and boys with epilepsy and headaches. Between mothers of healthy girls and girls with headaches, on the other

hand, no difference in the assessment of children's functioning was demonstrated only in the areas of Social Functioning and Psychosocial Health. Similarly, no difference was demonstrated in Social Functioning, Psychosocial Health and Total Scores in mothers of healthy boys and boys with headaches.

3.4. Evaluation of the quality of life of children regarding the child's age

3.4.1. Quality of life of children with epilepsy

Analyzing quality of life in the two age groups (8–12 and 13–18 years old), in the group of children with epilepsy, a difference was demonstrated in the assessment of children in the area of Social Functioning ($p = 0.0040$), Psychosocial Health ($p = 0.0091$) and Total Score ($p = 0.0114$). In the group of mothers of children with epilepsy, a statistically significant difference was demonstrated only in the Social Functioning ($p = 0.0219$). Younger children (63.84 points) and their mothers (60.22 points) evaluated Total Score lower than adolescents (69.9 points) and their mothers (64.10 points). Children from both age groups, as well as their mothers, evaluated the children's functioning in the area of School Functioning the lowest. Children in both age groups scored the overall quality of life (Total Score) higher than their mothers.

3.4.2. Quality of life of children with headaches

In the group of children with headaches, there were no statistically significant differences ($p > 0.05$) in quality of life of children with regard to age, formulated by children and

mothers. In the group of younger children, children and parents evaluated the lowest the area of emotional functioning. Adolescents evaluated the lowest the School Functioning and their mothers the Emotional Functioning. Children in both groups rated Total Score higher than their mothers.

3.4.3. Quality of life of healthy children

In the group of healthy children the younger children (84.78 points) and their mothers (79.12 points) assessed the quality of life higher than adolescents (82.42 points) and their mothers (75.07 points). Children from younger and older groups scored the overall quality of life (Total Score) higher than their mothers. In the group of younger and older children, both children and their mothers assessed the area of Emotional Functioning the lowest.

3.4.4. Comparison of the assessment of quality of life between children with epilepsy, healthy peers and the ones with headaches separately in two age groups: 8–12 and 13–18

In the group of younger and older children, a difference was demonstrated in the assessment of the functioning of healthy children and children with epilepsy as well as with epilepsy and headaches, in all areas of the PedsQL™ 4.0 questionnaire ($p < 0.05$). In contrast, a statistically significant difference between healthy children and children with headaches was demonstrated only in the evaluation of Social Functioning ($p = 0.0007$) in younger children and Physical Functioning ($p = 0.0166$) and Social Functioning ($p = 0.0294$) in older children.

In the group of mothers of younger children, a difference was demonstrated in quality of life of healthy children and children with epilepsy in all areas ($p < 0.05$), and between children with epilepsy and headaches in all areas except Emotional Functioning ($p = 1.000$) and Social Functioning ($p = 0.5312$). A difference was demonstrated in the assessment of mothers of older children regarding quality of life of children with epilepsy and healthy ones in all areas except Social Functioning ($p = 1.0000$), and between children with epilepsy

and headaches in all areas except Psychosocial Health ($p = 0.0975$). In the assessment of the quality of life of mothers of healthy children and children with headaches, a difference was demonstrated only in Social Functioning ($p = 0.0000$) and Psychosocial Health ($p = 0.0216$).

3.5. Agreement between children self-report and parents proxy-report

The answers were compared using Wilcoxon Test of children and parents in individual areas (Table 4).

A statistically significant difference was demonstrated in all areas of PedsQL™ 4.0 questionnaire in children with epilepsy and in healthy children, while in the group of children with headaches no such difference was demonstrated, except for the areas of Social Functioning and School Functioning.

To check the agreement of children's and parents' responses in PedsQL™ 4.0 questionnaire the compatibility factor Kappa-k was used. In the group of healthy children compatibility between children and their mothers ranged from 45.4% in the domain *I feel afraid or scared* and *I have trouble getting along with other kids* to 87.9% *It is hard for me to take a bath or shower by myself*. In the group of children with headaches, the lowest compliance concerned the response in the domain *I have low energy* (53.74%) and *I feel afraid or scared* (50.74%) and the highest was 90.23% (*It is hard for me to take a bath or shower by myself*). The Kappa-k compatibility factor between the responses of children with epilepsy and their mothers was between 47.2% and 79.6%. In all groups, the highest agreement of responses was observed in Physical Functioning, the lowest in Emotional Functioning.

4. Discussion

In our and other authors' studies, as well as in the original version, PedsQL™ 4.0 questionnaire shows the value of

Table 4 – Agreement between children's and parents' answers in individual areas.

PedsQL™ 4.0 Subscale	1. Children with epilepsy		2. Healthy children		3. Children with headaches	
	Median		Median		Median	
	Ch ^a	P ^b	Ch ^a	P ^b	Ch ^a	P ^b
Physical Functioning	81.25	71.88	87.50	87.50	75.00	75.00
Wilcoxon Test	$p = 0.0000$		$p = 0.0074$		$p = 0.0299$	
Emotional Functioning	65.00	60.00	75.00	65.00	65.00	60.00
Wilcoxon Test	$p = 0.0000$		$p = 0.0000$		$p = 0.0291$	
Social Functioning	70.00	65.00	90.00	75.00	85.00	85.00
Wilcoxon Test	$p = 0.0471$		$p = 0.0000$		$p = 0.2596$	
School Functioning	60.00	50.00	80.00	75.00	60.00	65.00
Wilcoxon Test	$p = 0.0000$		$p = 0.0037$		$p = 0.1956$	
Psychosocial Health	63.33	55.00	81.67	73.33	70.00	68.33
Wilcoxon Test	$p = 0.0000$		$p = 0.0000$		$p = 0.0333$	
Total Score	69.56	60.87	84.78	78.26	70.65	70.35
Wilcoxon Test	$p = 0.0000$		$p = 0.0000$		$p = 0.0095$	

^a Ch – children.

^b P – parents.

Cronbach's alpha coefficient for internal consistency above 70, which is a high rate of reliability [5,7,11,22-24]. Analyzing the functioning of children with epilepsy, headaches and healthy ones, during analysis of quality of life measured by PedsQL™ 4.0 questionnaire, it has been found that children with epilepsy evaluated their functioning the lowest, while healthy children scored it the highest. Similar assessments were formulated by the children's parents. At the same time, in all the studied groups, children assessed their quality of life higher than their parents. Baca et al. [25] compared the assessment of quality of life formulated by parents of healthy children and children with epilepsy. Parents assessed healthy children's quality of life higher. They assessed the children's behavior, psychosocial functioning, and general health condition higher. Other authors also observed a difference in functioning between healthy and chronically ill children [5,6,15,22]. In the study by Amiri et al. [21] healthy children, as well as their parents, assessed Total Score and all areas of the quality of life higher than chronically ill children with asthma, kidney disease and cancer. The quality of life of children with epilepsy is also assessed lower as compared to other chronic diseases. Comparison of children with epilepsy and with cancer showed that children with epilepsy were evaluated lower in the area of Social and School Functioning [1].

Socio-demographic factors affecting the quality of life are, for example, age, gender, and place of residence. Others relate to the disease, for example: type of epilepsy, the frequency of seizures, age at onset of the disease, duration of disease, medication side effects, cognitive functioning [2,4,9,12-14,18,19,24,26,27]. The effect of treatment on children's quality of life was studied by Haneef et al. [23], among others. Children with refractory epilepsy were assessed in individual areas of quality of life lower than children with epilepsy with controlled seizures. The occurrence of seizure itself also affects the quality of life. Authors studying children with single seizure and untreated epilepsy did not demonstrate significant differences between groups [24].

The variables common to the three analyzed groups selected included gender and age of the child. In the group of children with epilepsy, girls assessed their quality of life higher than boys. A difference was found in all domains of quality of life between the group of girls and boys with epilepsy and their healthy peers, to a lesser extent also in comparison to children with headaches. The area of quality of life where children with epilepsy had the most difficulty in the opinion of girls, boys and their parents was School Functioning, for healthy children and for girls with headaches – Emotional Functioning. Boys with headaches, similarly to boys with epilepsy, evaluated their functioning in subscale School Functioning the lowest. Aggarwal et al. [28] demonstrated no correlation between gender and the areas of quality of life scale (QOLCE). They found, however, that girls were slightly better at language, cognition, social activities and behavior. Other authors also observe significant difficulties with studying in children with epilepsy [6,14,18,23,26,27]. Mental health, cognitive abilities, memory in particular, and behavioral disorders are often listed as factors affecting the quality of life of children with epilepsy [4,15,19]. They also define social perception and relations with peers. Factors affecting

cognitive ability include frequency of seizures, younger age at disease onset, duration of disease [2,27,28].

The functioning of the child in school is also influenced by the teacher's approach which usually correlates with the teacher's level of knowledge regarding the disease [13,16,17]. Awareness of the disease process may have a significant impact on the relationship with the student. The teacher can observe changes in behavior, sleepiness and can also understand lower cooperation or absence of the child on the day of the seizure.

Functioning and learning are strongly influenced by medications. 70% of patients with proper choice of medication have long periods without seizures [15]. However, some patients experience more or less severe side effects of medications. New medications have a more beneficial effect on cognitive function. The negative correlation between the number of drugs and the memory was observed by Sabaz et al. [9], Mcewan et al. [16], Nadkarni et al. [18], Modi et al. [24]. Medication side effects and frequent seizures contribute to the reduction of social interaction and a sense of stigmatization among persons with epilepsy [15,16,19]. Difficulties with learning for a child with epilepsy can be eliminated by properly selected educational assistance, based on exercises aimed at the child's cognitive deficits [27]. The starting point should be the correct diagnosis in which cooperation between the neurologist (epileptologist) and a psychologist and a pedagogue is essential. Increasingly, the need is being stressed for cooperation with an occupational therapist and a physiotherapist who, through specific exercises, can eliminate deficits in psychomotor functioning of the child.

An equally frequent factor influencing the quality of life of children is age [19]. In our study, older children with epilepsy (13-18 years old) and their parents assessed Total Score and the individual functional areas (except Emotional Functioning) higher than younger children (13-18 years). In contrast to healthy children, their parents and parents of children with headaches assessed Total Scores in the group of younger children higher. Authors of earlier studies observed different effects of age on quality of life. Improvement of the quality of life with age observed Aggarwal et al. [28]. The researchers explain that this is due to a better understanding of limitations posed by the disease. Montanaro et al. [2] did not observe any effect of age and the type of epilepsy on quality of life. Other researchers have shown that a group of older children more acutely felt the negative impact of the disease on the psychosocial functioning [12,18,26].

The response agreement between children and their parents was determined with Wilcoxon and Kappa-k test. The analyses confirmed the differences in the perception of the functioning of children, especially in the area of Emotional Functioning. Felder-Puig et al. [1] obtained a similar outcome in children with epilepsy, as did Reinfjell et al. [3] and Varni et al. [10] in healthy children. Limbers et al. [5] showed the lowest agreement in the area of Physical Functioning, perhaps due to the selection of the group. Chronic diseases affecting children and teenagers included in the study could limit physical activity. Children in our study did not have such problems. On the other hand, they experienced anxiety about their health and social acceptance, but probably did not inform their parents, therefore the parents were not aware of the

negative experiences of their children. Comparison of the results with the group of healthy children in our study reveals that it is easier for parents to talk about objective things, such as learning difficulties or health problems, and they avoid or refer only briefly to the emotional sphere. Perhaps the parents as well as children include their anxieties in the area of subjective feelings, secrets or are embarrassed to disclose them. Emotional Functioning activity was assessed low, which may suggest that it is important for children and parents, but different problems are perceived. Little compliance of answers between children with epilepsy and their parents was also demonstrated by Verhey et al. [29] The greatest difference regarded present concerns and secrecy (CHEQOL-25 questionnaire).

An essential element indicated in our study is a high response agreement between children and their parents. The authors of the original version showed a moderate agreement [7,11]. Therefore, to understand the benefits of the study, it is important to remember that both versions should be treated as mutually complementary assessment of the functioning at another plane of perception. And they should not be applied alternatively. Only the children's health condition like much reduced IQ or little cooperation ability can explain collecting the information only from their parents [1].

5. Conclusions

In the assessment of children and mothers, the functioning of children with epilepsy was most similar to that of children with headaches, especially in the subscale Emotional Functioning and Physical Functioning.

The assessment of quality of life of children with epilepsy differed from that of their healthy peers in the group of girls and boys as well as in the group of younger and older children in all areas of PedsQL™ 4.0 questionnaire.

A medium response compatibility between children with epilepsy and their parents was shown in individual questions. The lowest compliance was found in the area of Emotional Functioning.

Author's contribution

Dorota Talarska, RN, PhD – designed the study, in charge of data collection, wrote the article.

Michał Michalak, PhD – performer the statistical analysis.

Patrycja Talarska, MA – in charge of data collection.

Barbara Steinborn, Prof., MD, PhD – designed the article.

Conflict of interest

None declared.

Acknowledgement and financial support

None declared.

REFERENCES

- [1] Felder-Puig R, Frey E, Proksch K, Varni JW, Gadner H, Topf R. Validation of the German version of the Pediatric Quality of Life Inventory (PedsQL™) in childhood cancer patients off treatment and children with epilepsy. *Qual Life Res* 2004;13:223-34.
- [2] Montanaro M, Battistella PA, Boniver C, Galeone D. Quality of life in young Italian patients with epilepsy. *Neurol Sci* 2004;25:264-73. <http://dx.doi.org/10.1007/s10072-004-0353-x>
- [3] Reinfehl T, Diseth TH, Veenstra M, Vikan A. Measuring health-related quality of life in young adolescents: reliability and validity in the Norwegian version of the Pediatric Quality of Life Inventory 4.0 (PedsQL) generic core scales. *Health Qual Life Outcomes* 2006;4:61. <http://dx.doi.org/10.1186/1477-7525-4-61>
- [4] Meneses RF, Pais-Ribeiro JL, Da Silva AM, Giovagnoli AR. Neuropsychological predictors of quality of life in focal epilepsy. *Seizure* 2009;18:313-9.
- [5] Limbers CHA, Ripperger-Suhler J, Heffer RW, Varni JW. Patient-reported Pediatric Quality of Life Inventory™ 4.0 Generic Core Scales in pediatric patients with attention-deficit/hyperactivity disorder and comorbid psychiatric disorders: feasibility, reliability, and validity. *Value Health* 2011;14:521-30.
- [6] Gandhi CS, Kundra S, Singh T, Chaudary GK, Khosia PP. Assessment of quality of life in children with asthma and epilepsy. *Pediat Therapeut* 2013;3:175. <http://dx.doi.org/10.4172/2161-0665.1000175>
- [7] Varni JW, Seid M, Kurtin PS. PedsQL™ 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care* 2001;39:800-12.
- [8] Ronen GM, Streiner DL, Rosenbaum P. Health-related quality of life in childhood epilepsy: moving beyond 'seizure control with minimal adverse effects'. *Health Qual Life Outcomes* 2003;1:36. <http://dx.doi.org/10.1186/1477-7525-1-36>
- [9] Sabaz M, Lawson JA, Cairns DR, Duchowny MS, Resnick TJ, Dean PM, et al. Validation of the Quality of Life in Childhood Epilepsy Questionnaire in American epilepsy patients. *Epilepsy Behav* 2003;4:680-91.
- [10] Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL™ 4.0 as a pediatric population health measure: feasibility, reliability and validity. *Ambul Pediatr* 2003;3:329-41.
- [11] Varni JW, Burwinkle TM, Seid M. The PedsQL 4.0 as a school population health measure: feasibility, reliability and validity. *Qual Life Res* 2006;15:203-15.
- [12] Devinsky O, Westbrook L, Cramer J, Glassman M, Perrine K, Camfield C. Risk factors for poor health-related quality of life in adolescents with epilepsy. *Epilepsia* 1999;40:1715-20.
- [13] McNelis AM, Johnson CS, Huberty TJ, Austin JK. Factors associated with academic achievement in children with recent-onset seizures. *Seizure* 2005;14:331-9.
- [14] Reilly C, Atkinson P, Chin RF, Das KB, Gillberg CH, Aylett SE, et al. Symptoms of anxiety and depression in school-aged children with active epilepsy: a population-based study. *Epilepsy Behav* 2015;52:174-9.
- [15] De Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy Behav* 2008;12:540-6.
- [16] McEwan MJ, Espie CA, Metcalfe J. A systematic review of the contribution of qualitative research to the study of quality of life in children and adolescents with epilepsy. *Seizure* 2004;13:3-14.
- [17] McEwan MJ, Espie CA, Metcalfe J, Brodie MJ, Wilson MT. Quality of life and psychosocial development in

- adolescents with epilepsy: a qualitative investigation using focus group methods. *Seizure* 2004;13:15-31.
- [18] Nadkarni J, Jain A, Dwivedi R. Quality of life children with epilepsy. *Ann Indian Acad Neurol* 2011;14:279-82.
- [19] Yong L, Chengye J, Jiong Q. Factors affecting the quality of life in childhood epilepsy in China. *Acta Neurol Scand* 2006;113:167-73.
- [20] Pal DK, Chaudhury G, Das T, Sengupta S. Predictors of parental adjustment to children's epilepsy in rural India. *Child Care Health Dev* 2002;28:295-300. <http://dx.doi.org/10.1046/j.1365-2214.2002.00278.x>
- [21] Amiri P, Eslamian G, Mirmiran P, Shiva N, Jafarabadi MA, Azizi F. Validity and reliability of the Iranian version of the Pediatric Quality of Life Inventory™ 4.0 (PedsQL™) Generic Core Scales in children. *Health Qual Life Outcomes* 2012;10:3. <http://dx.doi.org/10.1186/1477-7525-10-3>
- [22] Engelen V, Haentjens MM, Detmar SB, Koopman HM, Grootenhuis MA. Health related quality of life of Dutch children: psychometric properties of the PedsQL in the Netherlands. *BMC Pediatr* 2009;9:68. <http://dx.doi.org/10.1186/1471-2431-9-68>
- [23] 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 v 4.0 measurement model. *Epileptic Disord* 2010;12:275-82.
- [24] Modi AC, Ingerski LM, Rausch JR, Glauser TA. Treatment factors affecting longitudinal quality of life in new onset pediatric epilepsy. *J Pediatr Psychol* 2011;36:466-75.
- [25] 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 Health* 2010;13:778-86.
- [26] Eom S, Eun SH, Kang HC, Eun BL, Nam SO, Kim SJ, et al. Epilepsy-related clinical factors and psychosocial functions in pediatric epilepsy. *Epilepsy Behav* 2014;37:43-8.
- [27] Hermann BP, Jones JE, Jackson DC, Seidenberg M. Starting at the beginning: the neuropsychological status of children with new-onset epilepsies. *Epileptic Disord* 2012;14:12-21.
- [28] Aggarwal A, Datta V, Thakur LC. Quality of life in children with epilepsy. *Indian Pediatr* 2011;17:893-6.
- [29] Verhey LH, Kulik DM, Ronen GM, Rosenbaum P, Lach L, Streiner DL. Quality of life in childhood epilepsy: what is the level of agreement between youth and their parents? *Epilepsy Behav* 2009;14:407-10.