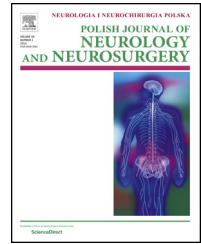


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## Original research article

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

**Dorota Talarska<sup>a,\*</sup>, Michał Michalak<sup>b</sup>, Patrycja Talarska<sup>c</sup>,  
Barbara Steinborn<sup>d</sup>**

<sup>a</sup> Department of Preventive Medicine, Poznan University of Medical Sciences, Poznań, Poland

<sup>b</sup> Department of Computer Science and Statistics, University of Medical Sciences, Poznań, Poland

<sup>c</sup> The Group of Secondary Schools no. 15 in Poznań, Poland

<sup>d</sup> Developmental Neurology Clinic, University of Medical Sciences, Poznań, Poland

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## 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.

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\* 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](mailto:pati.talarska@neostrada.pl) (D. Talarska).

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## 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, **Q4** **118**
- No other chronic comorbidities significantly affecting health, **120**
- IQ within or on the border of standards, **120**
- Learning in school. **124**

Additional selection criteria for children with headaches and epilepsy:

- Diagnostically confirmed Epilepsy (ILAE) and headache (IHS-2004), **128**
- Duration of disease – more than 6 months from diagnosis. **129**

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