

The usefulness of Quality of Life Childhood Epilepsy (QOLCE) questionnaire in evaluating the quality of life of children with epilepsy

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Abstract

Purpose: Evaluation of quality of life has become a frequently used method in treatment effects supervision. Quality of Life Childhood Epilepsy (QOLCE) questionnaire, which is completed by patients' parents, has been prepared for children with epilepsy. It enables to determine the quality of life in children aged 4-18 years.

The aim of the study was to show the usefulness of QOLCE questionnaire in evaluating the quality of life of children with epilepsy.

Materials and methods: 160 epileptic children, aged 8-18 years and their parents were examined in the Chair and Department of Developmental Neurology, K. Marcinkowski University of Medical Sciences in Poznań. QOLCE questionnaire was completed by parents and "Young people and epilepsy" questionnaire was designed for children.

Results: Reliability index of the complete questionnaire in own research and in the original amounted to 0.93 Cronbach α coefficient. Epileptic, drug-resistant children constituted 28% of the examined group. Parents of children with controlled seizures evaluated children's functioning in analyzed areas of quality of life higher.

Conclusions: 1. QOLCE questionnaire is a suitable tool to evaluate the quality of children's and adolescents' life. 2. The most significant differences in functioning of epileptic, drug-resistant patients and those with controlled seizures were observed in areas of cognitive processes and social activity.

Key words: children, epilepsy, quality of life, QOLCE.

Introduction

In medical research the index of treatment effects was the only coefficient considered important, which consisted in eliminating or alleviating painful disease symptoms. Now, there have been significant changes introduced. The attention has been attracted to the necessity of holistic perception of the human being [1]. It has resulted in the development of research on quality of life area. Ambiguity of the concept caused various conceptual assumptions of research. There are general – Medical Outcomes Study Short Form (SF-36), and specific tools used to estimate Health Related Quality of Life. There have been specific scales designed for children with epilepsy: Adolescent Sigma Scale, Hague Restrictions in Childhood Epilepsy Scale, Quality of Life for Adolescents with Epilepsy (QOLIE-AD-48), Quality of Life in Childhood Epilepsy Questionnaire (QOLCE) [2,3].

The aim of the study was to show the usefulness of QOLCE questionnaire in evaluating the quality of life of children with epilepsy.

Materials and methods

160 children with epilepsy, aged 8-18, and their parents were included into the examination, being held in the Chair and Department of Developmental Neurology, K. Marcinkowski University of Medical Sciences, Poznań. Criteria for the group: 8-18 years of age, Intelligence Quotient (IQ) – within limits or light mental impairment; types of seizures – partial or generalized epileptic seizure; treatment – monotherapy or politherapy; seizure incidence; therapeutic effects – drug-resistance or seizure control; absence of other chronic diseases or psychiatric episodes; education – the form of school obligation realization; parents' approval for examination participation.

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Research tools:

– Quality of Life in Childhood Epilepsy questionnaire for parents. Seven aspects were analyzed with the use of the questionnaire: child's physical activity, general feeling, cognitive processes, child's social activity, behavior, general health condition and general evaluation of quality of life [4]. Reliability index of the complete questionnaire in own research and in the original amounted to 0.93 Cronbach α coefficient.

– “Young people and epilepsy” questionnaire, completed by children enables collection of clinical information (e.g. when the first fit occurred, how often fits appeared, what medications are applied) and information concerning the knowledge of epilepsy symptoms and characteristics, necessary for both children and parents. Mann-Whitney test, Chi-Square test Fisher-Freeman-Halton test were used to verify the collected data.

Results

The examined group consisted mostly of children aged 8-13 (54 %). The ratio of girls and boys was equal to 1:1. 61 (51%) children presented primarily-generalized seizures, 22 (18%) patients had partial (simple and complex) secondarily generalized, partially complex occurred in 19 (16%), partially simple appeared in 12 (9%) and 6 (5%) patients were not classified at all. With the consideration to treatment effects, two groups were isolated: 34 (28%) children constituted a group of drug-resistant patients and 86 (72%) a group of controlled seizures. The analysis of particular QOLCE questionnaire parts resulted in the isolation of two, mentioned above, groups.

The “physical activity” of questionnaire part showed that children with drug-resistant epilepsy felt tired more frequently in comparison to children with controlled epilepsy and did not present physical fitness on the same level as peer – group members.

In “social activity” part, parents 25 (73%) of drug-resistant children and 71 (82%) of controlled seizures thought that their children did not talk about their disease with their peers.

The feeling to be accepted in peer-groups, was confirmed by their care-givers for 60 (70%) children with controlled seizures and 31 (36%) with drug-resistant epilepsy.

Parents 21 (62%) of drug-resistant children and 34 (40%) of controlled seizures confirmed difficulties in concentrating on any task for a longer period of time. The “Behavior” part, demonstrated that parents 29 (86%) of drug-resistant children and 58 (68%) of controlled seizures reported easiness of their children to irritate.

Application of Mann-Whitney test indicated statistically significant differences between drug-resistant and controlled seizures epileptic children's functioning in all analyzed areas: general feeling ($p=0.0015$), cognitive processes ($p=0.0133$), social activity ($p=0.0001$), child's behavior ($p=0.0073$). The statistical dependence between seizure incidence and school problems (Fisher-Freeman-Halton test $p<0.05$) and seizure incidence and acceptance (Chi-square test $p<0.05$) were indicated.

Discussion

QOLCE questionnaire, among many research tools, designed to measure the quality of life in children, is considered to demonstrate high psychometric values, e.g., reliability index for a complete questionnaire (Cronbach α coefficient) amounted to 0.93 [2-4]. Similar value was obtained in Polish version [5].

The usefulness of a tool by Sabaz et al. [4] for the measurement of quality of life of children with epilepsy is confirmed by obtained results of statistical analysis, e.g. dependence between children's quality of life and seizure incidence and polytherapy. Own research also demonstrated the dependence between seizure incidence and general evaluation of quality of life and acceptance in a peer group. Moreover, parents of the drug-resistant children with epilepsy estimated all analyzed areas of life lower than parents of children with controlled seizures.

Obtaining results are similar to those included in other authors' papers may constitute the indirect index of tool reliability. Sabaz et al. [4] received the highest indices of reliability in areas of social activity and cognitive processes.

The importance of social functioning in general evaluation of quality of life was also underlined by Henriksen [6], Owczarek and Jędrzejczak [7], Artemowicz et al. [8].

Walańczyk [9] defines epilepsy as one of the most frequent social diseases which impairs such areas of activities as education, professional work, family life, everyday life activities, social contacts, friendship and leisure time activities. The own research proved that 1/5 of drug-resistant children felt rejected by peers. Artemowicz et al. [8] remark that peers accept epilepsy in a friend when he himself accepts it, has extra interests and good results at school.

Parents of 1/3 of all examined patients with epilepsy reported school problems which were the results of disturbed memory and attention. Similar results were obtained by Aldenkamp et al. [10] and Devinsky et al. [11].

Conclusions

1. QOLCE questionnaire is a suitable tool to evaluate the quality of life in children and adolescents.
2. The most significant differences in functioning of drug-resistant patients and of controlled-seizure-patients were observed in cognitive processes and social activity.

References

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