



ORIGINAL PAPER

THE QUALITY OF LIFE FOR CHILDREN WITH EPILEPSY

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Abstract

Aim: The aim of this research was to find out the influence of this disease on the quality of life in children with epilepsy. **Methods:** To collect the empirical data, we used a standardized questionnaire concerning the quality of life – Quality of Life in Epilepsy for Adolescents (QOLIE-AD-48) designed for an age group of 11 – 18 years. The sample consisted of 70 participants. For statistical analyses, we used descriptive statistical methods. **Results:** The majority of participants rated their health status as good. Participants indicated difficulties in implementing more demanding activities; half of the participants did not have hardly any problems in meeting domestic and school assignments. For activities requiring concentration and understanding, participants reported the occurrence of problems rarely and sometimes. Participants were not greatly restricted by their parents in what they wanted to do, but half of the participants often did fewer things than they wished to do. They very often had someone who would give them advice, help them or with whom they may talk. In the area of self-perception, most participants did not feel imperfect due to epilepsy and only sometimes did they feel isolated from the others, having been always accepted the way they are. Participants did not agree with the claim that their disease could discriminate them when applying for a job or limit them in choosing a partner. They did not feel that epilepsy should make them mentally unstable. Participants were often concerned about an unexpected epileptic fit and injury during it; they were not concerned about unexpected death. **Conclusion:** The aim of nursing care is to ensure that the disease is best compensated for so that the child can lead a fulfilling life. The use of the assessment tools, in clinical practice, may help identify the patients' problems and limitations associated with the disease and find appropriate solutions.

Key words: epilepsy, quality of life in a child, quality of life assessment.

Introduction

Epilepsy is a relatively frequent neurological disease, in many cases having its onset as early as childhood. It represents a very heterogeneous group of diseases in terms of the type of the epileptic fit, frequency, etiology, onset and course of the disease, and the influence on the ill child's development and mental state (Svoboda, Krejčířová, Vágnerová, 2009, p. 492). Epilepsy treatment traditionally focuses on fit control and a decrease in the number of fits per year, which is the main aim of successful treatment, whilst the quality of life relates to a patient's overall well-being. Repeated fits cause patients cognitive, behavioural and emotional problems as well as a deterioration in the quality of life concerning social

functioning and a decrease in self-confidence (Tanriverdi, Poulin, Olivier, 2008, p. 339-349).

Dolanský (2000) suggests that the quality of life for patients with epilepsy is negatively influenced by the number of fits per their lifespan. Both children and adults with epilepsy have difficulties fitting into their peer group, because they have to follow a certain regimen, which other healthy people just do not understand and they can often lose interest in them. Patients with epilepsy particularly suffer from the following problems:

- Problems with medication use – medication treatment is associated with possible side effects, which have an influence on a child's overall behaviour. A child feels often tired and sleepy, their overall activity and attention are on the decrease, and vice versa, irritability increases and they tend to suffer from mood swings.

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- Psychological perception of epilepsy – the way a person perceives disease is decisive. If they accept their health status or fight the disease, or whether they ignore and resist it, put blame on themselves or others, and do not take into account the limitations and changes that this disease will bring about.
- Other people's attitude and associated social problems – also, in modern society, some people still have prejudice about epilepsy, which can cause a child's exclusion from society. Older children with epilepsy are concerned about having a fit in public or in front of their classmates, and that they will feel sorry for them or even be afraid of them (Vágnerová, 2004, p. 89, p. 138).

Aims

The aim of the research was to discover the influence of the disease on the quality of life in a child with epilepsy. Also, to establish whether there are any differences in the quality of life in girls and boys, how epilepsy affects a child's performance at school and the child's attitude towards the disease.

Methods

The sample consisted of 70 participants of the age of 11–18 years diagnosed with epilepsy.

Inclusion criteria for participating in the research was the child's age 11–18 years, to be diagnosed with epilepsy, a willingness to cooperate and sign a written consent form, and the miners' parents' consent to participation in the research.

The sample consisted of 35 girls and 35 boys. The average children's age was 14.2 years, $SD \pm 2.21$. The average duration of the disease was 4.03 years, $SD \pm 2.22$. Twenty participants reported that they had a fit in the past 4 weeks.

To collect the empirical data, we used a standardized *QOLIE AD – 48 Quality of Life in Epilepsy for Adolescents* questionnaire designed to evaluate the quality of life in children with epilepsy of the age of 11 – 18 years. The questionnaire consisted of 48 questions with the focus on assessing the overall health status, effects of epilepsy and of antiepileptic drugs, any concerns about death, accident or injury caused by a fit.

Participants answered the questions using the Likert scale (1-5), in which the options differed according to the type of question. The final part of the questionnaire included the child's demographic data

on age, sex, duration of disease, and the number of fits in the past 4 weeks.

The QOLIE AD – 48 questionnaire was available in an English version and, with the author's permission, it was translated into Slovak.

The research was conducted in an outpatient neurological clinic (in fact not a clinic but in one room that specializes in neurological patients – Czech “ambulance”) during examination.

The obtained empirical data was analysed using descriptive statistics (arithmetical mean, standard deviation).

Results

In general, participants rated their health status as *good* ($3.04 SD \pm 0.78$), both girls ($2.83 SD \pm 0.65$) and boys ($3.09 SD \pm 0.87$). When comparing their health status now and a year ago, 20 participants rated their current health status as the same and 50 participants rated it as better.

The answers given in Table 1 show how activities, which the child performs during a normal day throughout the past 4 weeks, had influenced their health status, and how the disease has affected the performance of the various activities in the past 4 weeks.

We found that demanding activities (e.g. running, gymnastic exercises, skating) *sometimes* caused difficulties for girls and boys. Our participants did not *often* feel limited by performing only moderate activities (e.g. going to school, riding a bike). They did light activities (carrying a school bag) without problems. Other activities (e.g. having a shower, going to and from school) did not cause any difficulties for the girls; however, 10 boys found doing these activities *sometimes* difficult.

We found that 20 girls and 15 boys *very often* did fewer things than they wanted to do. When doing school assignments, household chores or other sports, the participants felt only *sometimes* emotional or physical problems (13 girls and 10 boys). Children did not hardly have any problems with doing school assignments, did not stay off school without reason, and had no problem at school or outside of school due to their disease.

Table 2 gives answers concerning the influence of disease (in the past 4 weeks) on activities that require concentration and that are part of the teaching process.

As the research suggests, children with epilepsy only *sometimes* found it difficult to concentrate on the activity which they were doing. All girls reported that

they *never* had difficulties with thinking about something or problem solving. Boys' answers were not so straightforward and the answers *sometimes* (n = 15) and *rarely* (n = 15) prevailed. Participants indicated having a problem to remember a read text only *sometimes*. Mainly girls reported that the

epilepsy did not negatively influence their ability to express themselves, or more precisely they did not feel they were limited by disease when they wanted to express their opinions and thoughts, as 30 girls and 18 boys answered *never*.

Table 1 Performance of activities and their influence on child's health status

Items	Girls (n = 35)	Boys (n = 35)	Total (n = 70)
	Mean ± SD	Mean ± SD	Mean ± SD
Influence of demanding activities on health status	3.29 ± 1.03	2.97 ± 0.94	3.21 ± 0.99
Influence of moderate activities on health status	3.71 ± 0.70	3.66 ± 0.79	3.68 ± 0.74
Influence of light activities on health status	5 ± 0	4.57 ± 0.73	4.78 ± 0.55
Influence of other daily activities	5 ± 0	4.09 ± 0.81	4.54 ± 0.73
Doing fewer things than they wanted	1.57 ± 0.73	1.91 ± 0.94	1.74 ± 0.85
Doing school assignments, household chores	2.77 ± 1.20	2.77 ± 1.33	2.77 ± 1.26
Exerting extreme efforts during activities	4.29 ± 0.70	4.43 ± 0.73	4.35 ± 0.71
Staying off the school without reason	5 ± 0	5 ± 0	5 ± 0
Problems with teachers or other people	4.37 ± 0.72	4.11 ± 0.82	4.24 ± 0.78
Problems outside the school	5 ± 0	5 ± 0	5 ± 0

1 - very often, 2 - often, 3 - sometimes, 4 - rarely, 5 - never

Table 2 Influence of disease on learning

Items	Girls (n = 35)	Boys (n = 35)	Total (n = 70)
	Mean ± SD	Mean ± SD	Mean ± SD
Problem with concentrating on activity	3.57 ± 0.87	3.69 ± 0.71	3.62 ± 0.79
Problem with concentrating on reading	3.66 ± 0.79	3.83 ± 0.84	3.74 ± 0.82
Difficulties to think about something	5 ± 0	3.71 ± 0.70	4.35 ± 0.81
Difficulties with problem solving	5 ± 0	4.54 ± 0.50	4.77 ± 0.41
Difficulties with complicated projects	4.29 ± 0.70	4.09 ± 0.81	4.18 ± 0.76
Problem with remembering a read word	3.60 ± 0.64	3.49 ± 0.55	3.54 ± 0.60
Problem to adequately express oneself	4.71 ± 0.70	3.97 ± 1.08	4.30 ± 0.98
Problem with understanding a teacher	3.71 ± 0.70	3.86 ± 0.83	3.78 ± 0.77
Problem with understanding a read word	4.57 ± 0.73	4.17 ± 0.70	4.37 ± 0.74

1 - always, 2 - most of the time, 3 - sometimes, 4 - rarely, 5 - never

Fifteen participants had a problem with understanding schoolwork *sometimes* and 15 girls chose the option *rarely*. Twenty-five girls *never* had a problem with understanding what they were reading and 17 boys found it difficult only *rarely*.

All participants reported that they had someone who was always willing to help them and with whom they could talk about their problems when they could not cope on their own. Both groups of participants had a person who they could open their heart to about things they were concerned about. Twenty-five girls and 26 boys *very often* had a person available to talk and to solve their problems with. They were always accepted as they are.

Table 3 gives answers which indicate the influence of epilepsy and of antiepileptic drugs on the participants' life and how often they were limited due to epilepsy in the past four weeks.

Due to epilepsy, 10 girls and 12 boys had relatively *often* a problem in social environments. On the other hand, only *sometimes* children were feeling they were isolated from their friends. Twenty girls and 16 boys never missed classes due to epileptic fits and all participants *never* turned epilepsy to their advantage in order to avoid doing something they did not want to do. We also found that 20 girls and 23 boys *never* had a problem in taking antiepileptic drugs.

Twenty-two girls reported that their performance at school was *never* limited due to the disease and 19 boys indicated that their performance at school was *not often* limited. Thirty-four participants were *not often* limited due to the epileptic fits, and their independence was limited only *sometimes*. As the results show, girls did not consider epilepsy as a handicap which would limit them to a certain extent in their social life, or in meeting their friends. Boys felt the limitation only *sometimes*. Epilepsy and taking drugs limited our participants in doing sports or physical activities *sometimes*.

We found that the family limited our participants a little ($3.7 \text{ SD} \pm 0.68$) and did not allow them to do what they wanted to do due to their disease or taking the drugs which they have to take regularly. Thirty-

five girls and 18 boys reported that epilepsy *often* prevented them from doing new things. In the area of self-perception 20 girls and 19 boys did not consider themselves as imperfect due to epilepsy. Participants disagreed with the fact that the disease could discriminate them when applying for a job. Almost all participants (65) did not agree that epilepsy might limit them in choosing a partner and they did not feel that epilepsy would make them mentally unstable.

Participants indicated that they were *often* concerned about an unexpected fit, which may occur at any place any time. Thirty girls were *not often* concerned about death, while boys were *never* concerned about death. Thirty girls and thirty boys were *often* concerned about being injured during a fit.

Table 3 Influence of disease and medication

Items	Girls (n = 35)	Boys (n = 35)	Total (n = 70)
	Mean \pm SD	Mean \pm SD	Mean \pm SD
Influence of epilepsy and drugs on social activities	2.37 \pm 1.17	2.40 \pm 1.31	2.38 \pm 1.24
Influence of epilepsy on isolation from others	3.74 \pm 0.93	3.34 \pm 1.14	3.54 \pm 1.06
Missing classes due to fits or drugs	4.77 \pm 1.00	4.20 \pm 0.82	4.31 \pm 0.78
Turning epilepsy to one's advantage	5 \pm 0	5 \pm 0	5 \pm 0
Feeling embarrassed due to taking drugs	4.48 \pm 0.64	4.65 \pm 0.47	4.28 \pm 0.75
Limitation in a school performance due to e. and drugs	4.54 \pm 0.64	3.82 \pm 0.77	4.18 \pm 0.79
Limitation due to fits	3.60 \pm 0.59	3.77 \pm 0.67	3.68 \pm 0.64
Feeling one's independence being limited	3.97 \pm 0.90	3.71 \pm 0.84	3.84 \pm 0.88
Feeling of limitation in social activities	4.02 \pm 0.97	3.68 \pm 0.82	3.85 \pm 0.91
Feeling of limitation in sports	3.40 \pm 1.12	3.22 \pm 1.09	3.31 \pm 1.11

1- very often, 2- often, 3- sometimes, 4- rarely, 5- never.

Discussion

Epilepsy is a disease that has affected the human population for a very long time. Nowadays, there are several million people living with epilepsy all around the world, making it one of the most common and serious neurological diseases both in adults and children. It is a neurological disease, which limits a patient in various activities, and thus significantly changes their quality of life (Moráň, 2007, p. 10) The quality of life assessment does not only focus on evaluating the health status, but also seeing from a child's perspective and how they cope with this disease in mental, physical and social areas.

Provided that epilepsy is sufficiently controlled and adequate treatment is prescribed, children have no significant problem in doing activities. The length of the treatment is of importance, because when a child has been treated for epilepsy for only a few months, the effect of medication may not be the same as in a child who has been treated for several years (Talarská, 2007, p. 192-193). Most participants in our

sample rated their health status as good. Participants reported having difficulties in performing more demanding activities rather than doing moderate or light ones. Half of the participants did not have hardly any problem doing homework and school assignments and did not feel any emotional and physical strain whilst doing them. Participants did not stay off from school and did not have a problem at school or outside of school due to epilepsy. No participant had missed classes without reason during the past four weeks.

As Talarská's study (2007, p. 191-193) suggests, up to one third of the total of 160 children had frequent problems in remembering things and concentration during the lessons or when they were writing their homework. Most children with epilepsy gave a poor performance at school. It is suggested that one third of them perform in accordance to their abilities and 20% fail in fulfilling their tasks. Children with epilepsy have a worse relationship to school and are afraid of writing tasks or of being tested by the teacher, which are an inseparable part of teaching

(Svoboda, Krejčířová, Vágnerová, 2009, p. 496-497). Participants, in our sample, reported that only sometimes did they have a problem with concentrating on an activity, girls did not have any difficulties in thinking, most participants only sometimes had a problem with remembering a read text, with understanding schoolwork or a teacher, most of the girls did not have a problem in expressing their opinions and thoughts. Answers sometimes and rarely prevailed in this domain.

Chronic disease does not only affect a child's life, but also the life of their parents. Parents' opinions, anxiety and concerns about their child being at risk, and overall child-rearing attitudes significantly affect a child's emotional perception and health status. Parents are often overprotective and inadequately feel sorry for their child, trying to fulfil their every wish. In order to protect them from adverse health complications, parents often, in good faith, draw a child's attention to all the limitations they may face. When a child does something they should not do, they suffer from fear. Mental complications that may develop in a child are not beneficial to treatment and aggravate it (Langmeier, Balcar, Špitz, 2010, p. 341-346; Matějček, 2001, p. 64-65). We found that the parents did not limit our participants in what they wanted to do, but, on the other hand, half of the participants indicated that they very often did fewer things than they wanted to do. Epilepsy often prevented them from doing new things.

A patient should take an active part in all activities and household chores. Parents should prepare their child for independence and responsibility for himself/herself. Several research studies confirmed that people with a lower level of social support are more likely to suffer from health problems than those who are given greater support from their family (Heretik, Heretik jr. et al., 2007, p. 550-551). As participants' answers suggested, children very often had someone who could give them advice or help them, and with whom they could talk about their problems.

Thomas and Nair (2011, p. 158-163) point out that epilepsy may be perceived as a normal disease until a child or an adult has a fit in public. When this happens, the person is often perceived as someone to be afraid of and is often discriminated against in society. According to Sherman's study (2009, p. 17-24) people with epilepsy feel more socially isolated either in their leisure time, during sports, family activities or when they are looking for a job compared to healthy people.

Adolescents and children in puberty are depressed by the idea of being excluded from their social

environment due to their disease. They are often misunderstood and scorned by their peers, which may result in an inferiority complex. Every child is aware of their disease and experiences it differently. Disease does not only affect individual organs, but the whole personality. A child, as well as an adult, perceive a change in their lives and try to cope with it. A child may be touched by their parents' uncertainty and anxiety, their moods and attitudes, the way the parent acts, and changes in their behaviour towards them (Matějček, 2001, p. 12-17). Adolescents with chronic disease find this stage of life especially difficult because they are starting to develop a relationship towards both their personality and the disease which they are a part of. They realize the limitations in various areas that disease brings and think about their value (Vágnerová, 2008, p.154). In the area of self-perception, the research showed that most participants did not consider themselves to be imperfect due to epilepsy and only sometimes felt isolated from others. As the results suggest, girls did not consider their disease as a handicap that would limit them to a certain extent in their social life or in meeting their friends. Boys felt this limitation only sometimes.

Studies of social attitudes towards patients with epilepsy in France showed that most young people did not want to meet or spend their leisure time with children with epilepsy. That is why it is important to look for the causes of social prejudices against these children (Dulac, Ictal, 1996 In: Owczarek, 2007, p. 122-124).

Making career choices can also be affected by epilepsy, particularly in a job where a good health status is needed. Sometimes parents may find difficult to direct their child properly and fulfil a child's dream they have had since early childhood. That is why mutual communication between a parent and a child is important in order to find the right solution concerning the child's future. People with epilepsy should not work at great heights and with open fires. Jobs, such as a soldier, policeman, diver, fireman, pilot, safeguard, professional driver etc. are not suitable working positions for people with epilepsy. As fits can sometimes be triggered off by inadequate sleep, a person with epilepsy should not work in a three shift working schedule (Svoboda, Krejčířová, Vágnerová, 2009, p. 500-512).

When a child decides which school to attend, it is vital to consult a doctor first who will help find an appropriate field of study that does not pose any risk to the child and on which a child can focus, People with epilepsy have difficulties in finding a job, although health professionals claim that they are able

to give the same working performance as healthy people. They are more likely to be unemployed and they often have to do a job which does not correspond to their qualifications. It is often the case that a possible employer sees their disease as a risk and prefers to take on an applicant who does not have any chronic health problems (Matějček, 2001, p. 55-64). Participants did not agree with the fact that epilepsy might discriminate them in applying for a job.

Conclusion

In nursing care for children with epilepsy, it is important not to focus only on the disease symptoms, but also on how the child himself/herself perceives the disease. Early diagnostics and treatment will eliminate any complications and the effects of epilepsy which may influence overall health status. The aim of nursing care is to control the disease as much as possible, so that a child can lead a full life. Using assessment tools, in clinical practice, may help to identify a patient's problem and limitations which the disease brings about, and to look for an adequate solution.

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Ethical aspects and conflicts of interest

The authors declare that the work has no conflict of interest and that all ethical aspects of the research were met. The Ethics committee of the Jessenius Faculty of Medicine in Martin, Comenius University in Bratislava has given permission for the use of a questionnaire. Participants, who were willing to cooperate, were included in the research; miners' parents signed a written consent form.

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