

The psychosocial impact of epilepsy in Czech children: what are causative factors of differences during ten years interval?

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Dedicated in memoriam to Jiří Dolanský, co-founder of "EpiStop".

ABSTRACT – Epilepsy is the most common chronic neurological condition in childhood. In this paper we present results of analysis of a comparative survey, using data derived from 34-item questionnaire completed by 2 groups of children with epilepsy from the whole Czech Republic. The first group (1 217 children) was invited to complete the questionnaire in 1995, the second group (612 children) in 2004. The greatest attention is usually paid to the “biological” characteristics of epilepsy like control of seizures or adverse effects of medication. However, children’s perception or feelings about epilepsy and interferences with their everyday life (school, socializing, holidays, leisure time...) seem’s to be at least of the same importance. That’s why our main objective was to examine exactly such psychosocial aspects of quality of life (QOL) and we targeted to identify any potential shift of children’s perception over the last 10 years. Three principal informations arised out of this analysis: during the 10 years period adverse effects of antiepileptic drugs (AEDs) became less frequent, probably in accordance with the shift towards the use of new AEDs. The second group in feels to be less restricted in personal, social and sporting activities – most probably because they have generally achieved better control of seizures. The children admitted better awareness about epilepsy among teachers and friends over 10 years. The study has provided important information about the level of psychosocial QOL of children with epilepsy in the Czech Republic and showed a slight shift towards optimism in thinking and feeling of children with epilepsy during the 10-years period.

Key words: epilepsy in children, psychosocial burden, quality of life, antiepileptic drugs

Circa 10 million children worldwide, 60 000 school children in the UK and approximately 13 000 in the Czech Republic suffer from active epilepsy (Hoare 1995). It is the most common serious chronic neurological disorder in childhood, a chronic condition with numerous social and psychological consequences. More precise etiologi-

cal diagnosis, more sophisticated neuroimaging, new antiepileptic drugs (AEDs), better understanding of syndrome-specific efficacy profile of AEDs, etc., all this has over the past decade provided much better management of epilepsy. However, it still remains to be one of the most socially discriminating diseases.

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That's why the first project of task force group EpiStop has targeted the subjective feelings of Czech children with epilepsy. We recruited children with epilepsy from the outpatients child neurology departments throughout Czech Republic. We carry out a survey, using questionnaire completed by either children themselves or by their parents. The data were then derived from the comparison between 2 groups of children with epilepsy: the first group ("O" = old) being asked to complete the questionnaire in 1995, the second one ("N" = new) in 2004.

We focused on how children and adolescents perceive the impact of epilepsy and AED treatment on the quality of their lives and tried to compare the possible shift of this perception during the past 10 years. Our objective was to examine the social related quality of life of children with epilepsy by specific questions: how children and adolescents view the impact of epilepsy and AED treatment on the quality of their lives, what are their attitudes and fears regarding epilepsy, what are common problems they're encountering in their everyday lives, how do they evaluate general population's (especially people from their close surroundings) awareness of epilepsy or how do they feel about people's behaviour and approach towards them? And finally, is there really a positive progress in perception of children's QOL in conformity with the rapid improvement of managing epilepsy over the past 10 years, including the ten years educational role of the Task Force "EpiStop", as we believe?

Methods

We compared 2 different groups of children with epilepsy at the interval of 10 years. All the children were recruited from the outpatient services of the child neurology from the whole Czech Republic, distribution in different regions corresponded with a size of its population. 1 272 children (around 10% of all children with epilepsy) aged 6 to 17 years participated in the study in 1995 and 612 children aged 6 to 17 years in 2004, both females and males equally represented. Children and/or their parents were to answer 34-item questionnaire. By estimation 6 000 questionnaires were distributed in the "old" study in April 1995 ("O"), response rate was approximately 22%. In the "new" study in 2004 ("N") approximately 3 400 questionnaire were distributed with the response rate of about 18%.

The originally designed questionnaire was developed to provide data about psychosocial aspects of quality of life (QOL) of children with epilepsy in Czech Republic. The questionnaire consists of several groups of questions concerning specific aspects of QOL. The main areas covered include: feelings about epilepsy and its manifestations, effects of pharmacotherapy, difficulties in normal life, leisure time and school activities, children's understanding to their illness, the level of knowledge and awareness about epilepsy among parents, teachers and friends, and children's expectations to the future.

The completed questionnaire were controlled, encoded and processed by PC (software SPSS for windows). The answers were sorted by standard identification variables such as child's age, child's gender, severity and duration of seizures.

Results

We categorized the informations resulting from our questionnaire into several domains.

The first one describes mainly basic characteristics of respondents, clinical manifestations of their seizures (frequency, duration of particular seizure, duration of treatment, etc.) and pharmacotherapy.

Both genders were represented approximately equally in both monitored groups. Age categories distribution was similar as well: the samples consisted of 29% ("O") and 26% ("N"), respectively, of children younger than 10 years, 45 and 43%, respectively, of adolescents between 11 and 15 years old, and 24 and 28% , respectively, of older teenagers (*table 1*).

Treatment duration was unfortunately available only in group "N": 15% of children were treated less than 1 year, 24% 1 to 3 years and 39% more than 3 years, 22% didn't provide an answer. As concerns frequency there was in both groups a majority of children (65%) who reported only less than 4 seizures per year, on the other hand only a minority (11%, resp. 8%) reported more than 1 seizure per week. The biggest difference was in number of seizure-free children – only 4% in the group "O" in comparison with 45% in the group "N" (*table 2*). The duration of seizure was usually only a few seconds (39 and 38% respectively) or a few minutes (28 and 35% respectively). Only 8% of children from group "N" reported seizures prolonged more than 5-10 minutes, in contrast to 21% of children from group "O" (*table 3*).

Table 1. Age of responders.

	n		%	
	S	N	S	N
≤ 10 years	275	157	29	26
11-15 years	424	261	45	43
> 15 let	226	171	24	28
No data	14	23	2	4

p = 0.118.

Table 2. Seizure frequency.

	n		%	
	S	N	S	N
2 per week	79	53	8	9
4 per year	128	50	14	8
Less frequent	614	401	65	65
Seizure free	36	273	4	45

p = 0.001.

Table 3. Duration of seizures.

	n		%	
	S	N	S	N
Few seconds	363	233	39	38
Few minutes	261	214	28	35
5-10 minutes or longer	198	49	21	8
No data	117	116	12	19

$p < 0.001$.

As concerns pharmacotherapy it is apparent that most of the children (97 and 94% respectively) are treated with medication, with the prevailing form being tablets. Only a few children (who are all seizure-free) were without medication (3 and 4% respectively). Concerning the effective substances used there is an obvious shift towards newer AEDs (*figure 1*). The most frequently used drugs still remain broad-spectrum carbamazepine (CBZ) and valproic acid (VPA). Though the importance and frequency of use of each has changed. While in 1995 50% of children from group "O" were treated by CBZ followed with nearly 40% of children taking VPA and their derivatives (13% taking combination of both), in 2004 VPA has unambiguously won being prescribed to 61% of children. And CBZ (23% of group "N") was equalled by lamotrigine (LTG; 20% of group "N"). Topiramate (9.5% from "N") was the next one from new AEDs on the increase.

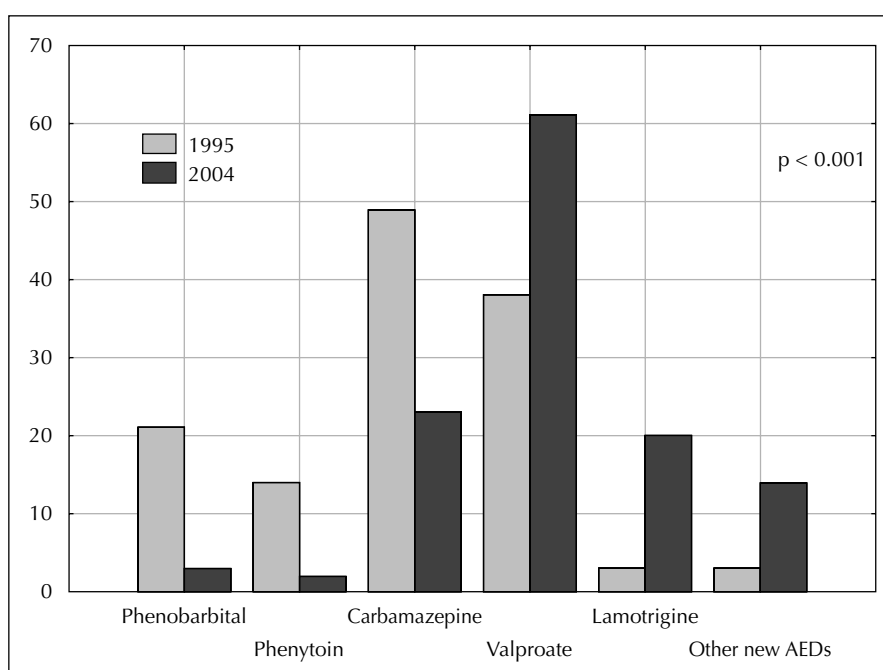
The range of adverse effects allways remained the same but the adverse effects became less frequent (*figure 2*):

fatigue (38 and 21% respectively), irritability (20 and 6% respectively), poor concentration (21 and 8% respectively), headache (15 and 6% respectively) and dizziness (7 and 2% respectively). Nevertheless 40% of children didn't report any adverse effect. Complementary medication used was similar (vitamines, microelements and nootropic).

Compliance seemed to be very high, 95 and 93% of children respectively reported they always or almost always do take their medication as prescribed (only minority of children - 18%, resp. 9% - has to take the medication during school-time). Also, the majority of children evaluate the treatment positively and the confidence in the effectiveness of AED is still high (58 and 55% respectively - AEDs definitely helped them; 33 and 31% respectively stated AEDs probably helped them).

The second domain is children's general perceptions of epilepsy and seizures themselves and dealing with difficulties in everyday life, leisure time and school activities.

62% and 44% of children, respectively (the difference probably due to missing data for 40% of children in the group "N") labelled their epilepsy as mild or very mild – probably because of the combination of two factors: the majority of children reported low frequency and short duration of seizures. Considering the fear of seizures, nearly a half of children (49 and 47%, respectively) denied having any anxiety of recurrent fits at all or admitted only a minimal anxiety – those were mostly children with only a few seconds-lasting seizures and mostly males.

**Figure 1.** The profile of pharmacotherapy (% from total AEDs use).

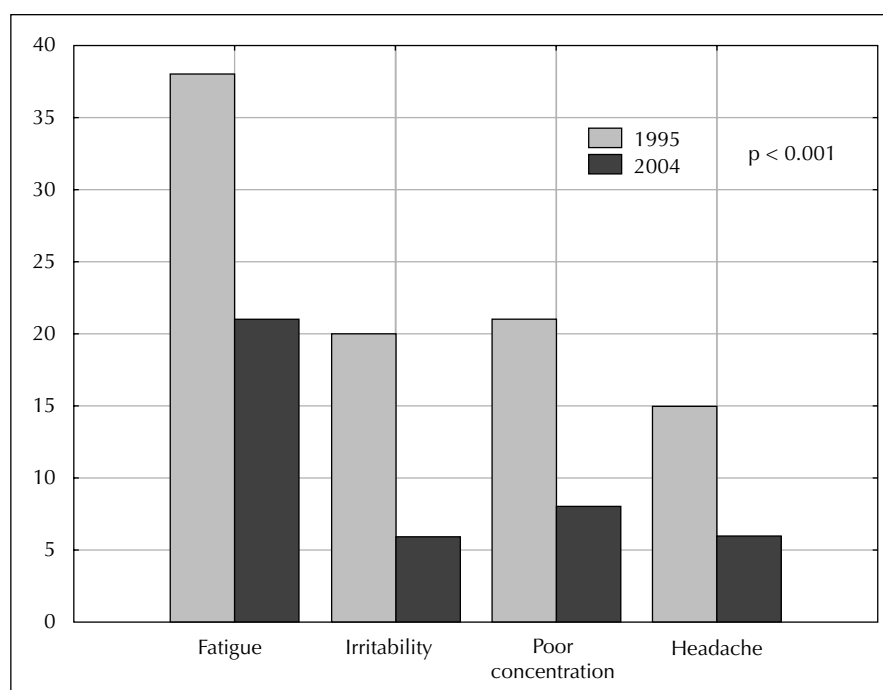


Figure 2. Do you feel some adverse events?

On the contrary there is a not-negligible proportion of permanently or nearly permanently frightened children (23%, resp. 15%) – in this group preponderate females and children with prolonged seizures. Subjective feelings of course depends on the age: the youngest describe their feelings more like being frightened and helpless while older children define their feelings more like being worried. Nearly half of the children (50%, resp. 47%) reported total retrograde amnesia for the time of lasting seizures. And most of them (63%, resp. 83%) are not able to classify their seizures. Only 21%, resp. 14% of children experienced an injury in consequence of seizure.

The majority of children are very much aware of being more or less restricted in some activities of daily living, sport and school. In general, they feel slightly more limited in sports than in usual daily activities. A bit more than one quarter (“O”), resp. one fifth (“N”) of children reported that the epilepsy always or nearly always restrained them to practice sports, especially swimming. Seven to 18% can not play outside with their friends, participate in school trips or spend holidays as they would like to because of epilepsy. On the other hand it is gratifying that there is quite large proportion of children (37, respectively 55%) which does not feel to be restricted in practising sports. In the concrete 43 and 62% respectively feel free to swim without or nearly without limitation and even 58 and 70% respectively, do not feel any problem riding a bike (*figure 3*). Even more positively is how children see leisure activities: half to two thirds (“O”), resp. nearly three quarters (“N”) of children

does not feel they are restricted. Those proportions are approximately the same as concerns males and females. Nearly one third of children reported they never experienced school and learning problems in connection with epilepsy and another 10 to 20% of children stated they almost never experienced such a problem. And conversely only circa 10 and 3% respectively, of children declared they have problems in concentrating at school, to learn new things, to solve requested projects, to prepare homework, etc., 70% of the children had never been sent home because of an epileptic seizure, while only 4 and 2% respectively, have been sent home frequently. Nearly half of the children had never missed school because of epilepsy, while only 13 and 9% respectively have missed more than 3 weeks.

The third set of information relates to children’s understanding to their illness, awareness about epilepsy among parents, teachers and friends.

57%, resp. 50% of children still have no knowledge what is the cause of their epilepsy, what evokes their seizures. This implies only one third of children have some idea about their illness! Nonetheless they do admit that during last 10 years there has been an increase in efforts of doctors to explain their illness – 41% children *versus* 66% have received information and only 18% of children from the group “N” claimed they had never been educated about their illness (*table 4*). Half of children admit they could understand what has been said (49%, resp. 57%), on the other hand only 15%, resp. 8% of children did not understand at all.

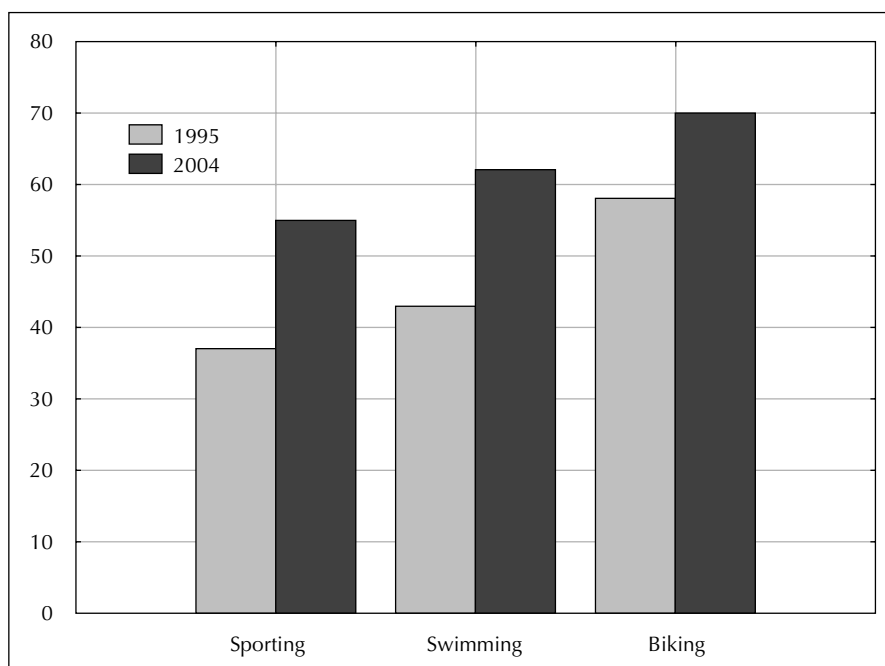


Figure 3. Do you feel free to make sport, to swim or to ride bike?

As concerns the knowledge about epilepsy three quarters of children presume their parents understand epilepsy. The same doesn't go for their friends and their teachers. Nevertheless children admit awareness of teachers and friends is improving: 33%, resp. 49% of children think their teachers understand epilepsy and 19%, resp. 35% of children feel their friends understand the condition (figure 4).

Children with epilepsy can feel their neighbourhood is trying to help them in coping with their illness. Again the most helpful group of people is parents (90%, resp. 84%). 30%, resp. 46% of children feels their friends to be supportive. The support of teachers is a bit more complicated to evaluate: in general 36%, resp. 45% of children think their teachers do help or assist them. But there is a marked dependence on the age: half of the children under the age of 10 years appreciate the support of their teachers, but only one quarter of those over the age of 15.

And the last, but not least, topic is focused on children's expectations to the future.

Table 4. Did you obtain information what is epilepsy?

	n		%	
	1995	2004	1995	2004
Yes	381	403	41	66
No	486	110	52	18
No answer	72	99	7	16

$p < 0.001$.

A majority of children with epilepsy still expect very long duration of their illness. 84% children from "O" expect their illness will last more than few years (22% even think they will suffer from epilepsy till the end of their lives). 46% children from "N" expect duration approximately a few years to circa ten years, and 11% of them expect epilepsy to be with them their whole life. Of course more optimistic about duration of their disease are children with less frequent seizures or children who are seizure-free and as well the younger children.

As regards restrictions in their future personal and social life: 58%, resp. 61% don't feel having any problem to get on together with mates or other children; two thirds of children feel they won't be restricted in getting married (67%, resp. 66%) or having children (62%, resp. 64%); 48% resp. 58% don't expect any restriction in travelling; but only 23%, resp. 33% of children think they will be able to get a driving licence. As concerns their cognitive or intellectual functions and professional life: 56%, resp. 69% of children think they should be as clever as healthy children. On the contrary, 36% from the group "O" (only 16% "N") admit they would do better at school if they did not have epilepsy. 43%, resp. 42% of children believe they will be able to have a job they select.

Discussion

The quality of life is definitely a multidimensional issue. As concerns epilepsy in children, four main dimensions of quality of life are generally accepted: neurological, psy-

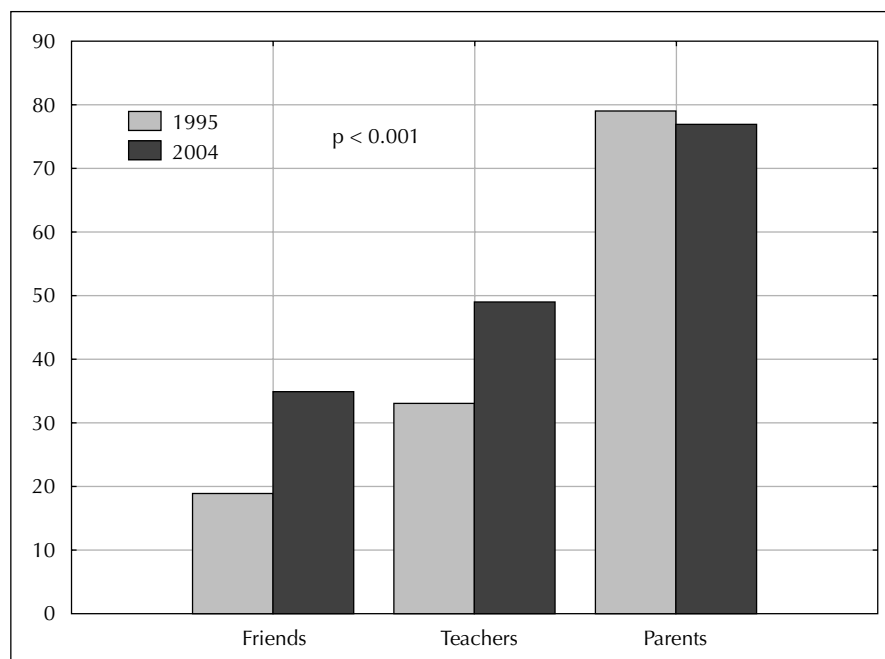


Figure 4. Do your friends, teachers and parents understand epilepsy?

chological, social and educational (Bailet and Turk 2000; Camfield *et al.* 2003; Devinsky *et al.* 1999; Hoare and Russel 1995; Sillanpää and Shinnar 2004; Shackleton *et al.* 2003; Yong *et al.* 2006). The majority of studies focus on health-related quality of life – HQOL (Räty *et al.* 2003; Ronen *et al.* 2003; Sabaz *et al.* 2003), and fewer authors have so far analyzed economic aspects (Radhakrishnan *et al.* 1999; Schachter 2000) of chronic epilepsy. In this study, we focused on so-called psychosocial aspects of living with epilepsy. The quality of life and psychosocial functioning in people with epilepsy have been investigated in many studies (Baker 2002; Berto 2002; Hoie *et al.* 2006; Hoare and Russel 1995; Mims 1997; Sabaz *et al.* 2000). Nevertheless, because of the lack of a standardised approach, it is difficult to compare results and some authors have recommended considering seizure frequency alone as a measure of well-being in people with epilepsy (Berto 2002).

Recent studies have shown that people with well-controlled seizures are less likely to report psychosocial problems, and people in seizure remission (> 2 years seizure free) report quality of life not significantly different from those without the condition (Baker 2002). This hypothesis has been confirmed in our study – the group of patients completing the questionnaire in 2004 (group “N”) feels to be less restricted in personal, social and sport activities, most probably due to the fact they have generally achieved better control of seizures (45% seizure-free children in group “N” versus 4% in group “O”). Understandably, there is a small difference according to child’s age and according to frequency and duration of seizures –

the older the children are or the shorter and less frequent fits the children have, the less limited they feel by epilepsy.

Concerning AEDs, our study suggests a remarkable shift towards newer antiepileptic agents. A comparison of pharmacotherapy profile in the Czech Republic with data from different countries presented by Radhakrishnan (Radhakrishnan *et al.* 1999) is shown in table 5. Although the data from different countries cannot be directly compared due to the lack of homogeneity of the samples, interpretation of similar proportions of older and newer AEDs in the Czech sample of 1995 and the Dutch sample of 1996 on one side, and in the Czech sample of 2004 and the French sample of 1992 on the other, might be of interest.

Table 5. Profile of antiepileptic drugs in different countries: % of total for each AED.

Country	PB	PHT	CBZ	VPA
USA (1994)	18	48	31	13
UK (1991)	18	31	31	24
The Netherlands (1996)	12	24	49	25
France (1992)	10	-	33	59
Italy (1988)	31	16	25	14
South India (1999)	8	25	44	21
Czech Rep. (1995)	23	15	49	38
Czech Rep. (2004)	3	2	23	61

Figures are approximate, and totals may exceed 100% because of polytherapy. These figures are not strictly comparable as they are from different sources of patients. PB: phenobarbital; PHT: phenytoin; CBZ: carbamazepine; VPA: valproate.

It appears the newer AEDs have 2 to 2.5 times fewer adverse effects (headache 15 and 6% respectively, poor concentration 21 and 8% respectively). The patients also admitted less impairment on cognitive functions. This appears to be in line with fewer adverse effects of new AEDs, the use of which was on increase. On the other hand, because of this increase of the use of newer AEDs during the last decade, we could expect fewer difficulties at school in the group of patients answering the questionnaire in 2004 (group "N"). With regards to their cognitive or intellectual functions and professional life, 56 and 69% of children respectively felt to be as smart or clever as healthy children. Nonetheless, one third of children felt their school achievements were not the same as those of their healthy schoolmates. This probably results in these children being quite realistic with regards to their expectations of professional careers. The Cleveland's authors assessed "parent- and patient-validated concern for pediatric epilepsy QOL" (Arunkumar *et al.* 2000) and found that it is important for children with epilepsy to feel free to engage in sporting activities. According to this aspect, one of the most positive results of the present study is the increase of proportion of children not limited in sporting activities.

With regards to awareness about epilepsy among parents, teachers and friends, only 33% of patients in group "O" (completed questionnaire in 1995) thought their teachers understood epilepsy. This number of responders is lower in comparison of some other studies (Millogo and Siranyan 2004) and probably does not reflect the real teachers' knowledge and attitude towards epilepsy. The children from the 2004 group appreciated better teachers' and friends' knowledge about their disease.

Conclusions

Children with epilepsy have relatively compromised quality of life and focusing care of these children simply on control of seizures with minimal adverse drug reactions, may not address the full range of child's emotional and behavioural difficulties. Even though the questionnaire used in the present study was not validated, we still believe that the study has brought important data about the level of psychosocial quality of life of children with epilepsy in the Czech Republic. Notwithstanding other information, these data suggest there has been slight shift towards optimism in thinking and feeling of children with epilepsy during these last 10 years. Our data also pointed out several specific topics for future educational programmes, potential future activities of EpiStop. □

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