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Utility of camp for children with epilepsy: a retrospective

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Objective: The aim of this study was to evaluate the benefits of educational and recreational camping programs for children with epilepsy.

Method: A retrospective review of data collected from all children attending annual epilepsy camps organized by the Croatian Epilepsy Association and the Zagreb City Office for Health during 8 years was performed. Children included were between 6 and 18 years of age. The staff of the camp includes child neurologists, a psychologist, neurology nurses and trained volunteers. Educational activities are designed to improve children's knowledge of epilepsy, importance of taking medication, academic choices, suggested employment, and regulations regarding driving laws. These issues were discussed in groups or in single sessions, depending on the case. Other activities included supervised swimming, team sports, fun activities and games, arts and crafts and entertainment such as disco or movie night.

Each of the participants filled out three questionnaires 1. General data questionnaire and pre-camp knowledge test; 2. Camp satisfaction questionnaire and post-camp knowledge test; 3. Questionnaire on adaptation to epilepsy in young people.

Results: The analyses of surveys and tests showed that only 75% of children in camp knew that they had epilepsy. In 10% of children, friends and distant family members did not know about epilepsy. Comparing the knowledge test before and after the camp, the average percentage of correctly solved tasks on the first test is 65%, and on the second 87%. The answers in the questionnaire on adaptation to life with epilepsy are indicators of strong stigma in children with epilepsy.

Conclusions: The main accomplishment of the camp was for children to gain confidence that they can reach their full potential in life and to feel equal to their peers in every aspect of life.

Key words: EPILEPSY; QUALITY OF LIFE; ADAPTIVE BEHAVIOUR; RECREATION THERAPY

BACKGROUND

Epilepsy has a prevalent occurrence in childhood, since 60% of all patients suffering from epilepsy are children under the age of 16 (1, 2). Children with epilepsy are exposed to many stressors, including limitations in daily functioning, demanding treatments, frequent hospitalizations, isolation and a lack of age-appropriate activities. They also have the duties and obligations in the process of growing up: school obligations, development of independence, creation of an identity and establishment of adequate relationships with peers. These problems significantly increase the likelihood of developing psychological problems, such as depression, anxiety, psychosis, attention and behavioural problems, as a result of psychosocial and clinical factors, and the development of stigma, that may affect the psychological adaptation to the disease and the course and outcome of the treatment. Several studies have shown that education and support groups create positive attitudes to successfully

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adapt to the disease and reduce anxiety and depression (3). In addition, educational and rehabilitation camps for children and adolescents suffering from chronic diseases are organized around the world and have proven to be extremely beneficial for the children and their caregivers (4).

Although many children with well-controlled epilepsy live normal lives but the longevity of the disease can lead to impaired quality of life (5). The psychosocial problems manifests in many ways. In such children, the first things that come to the fore are reduced learning difficulties, activities in everyday life, daily skills and personal independence. Difficulties in communication lead to behavioral disorders, all of which can lead to social isolation, anxiety, and depression (6).

The primary purpose of organizing camps for chronically ill children is to provide psychosocial support necessary for good adaptation to the disease. Research in the field of health psychology shows that social adaptation is one of the most sensitive areas in the growing age and that relationships with peers have a significant impact on adaptation to the disease (7).

The camp is an ideal place for a safe environment to meet peers who are living with the same illness, to exchange experiences, to re-evaluate treatment options, strengthen their confidence, and help develop habits that are useful even after they return home. For some children this may also be the first time to spend time without parental supervision. It might be their first chance to take care of themselves and get involved in joint work of all camp attendees on demystification of epilepsy and its stigma. The camp also enables the detection of children prone to risky behaviour and problems that require greater attention or intervention (8, 9).

METHODS

General design and patient population

A retrospective review of the data collected from all children who attended epilepsy camps during 8 years was performed. The education and rehabilitation camps, organized by the Croatian Association for Epilepsy, the Department of Paediatric Neurology, the Paediatric Clinic, the Zagreb UHC and the Sestre milosrdnice UHC with the sponsorship of the City Office for Health of the City of Zagreb designed to promote socialization and raise independence in children aged 6 through 18 with epilepsy. Children had 24 hour a day supervision by several child neurologists, a clinical psychologist, two nurses and two animators. (4, 9)

The program of the camp included educational, entertainment and sports activities aimed at improving the mutual acquaintance of peers with the same illness, acquiring new knowledge of the disease, and improving psychological adaptation to the disease (4, 9).

Over the next years, the camp was held at different locations – from the seaside to the mountains, thus offering children various activities and experiences.

Participants were eligible for recruitment in camp if they were aged 6 years to 18 years, had a well control of epilepsy (in whom seizures are well controlled by their antiseizure medication and had less than one seizure per month) and regularly took one or more antiseizures medications. Patients were selected by a competent child neurologist with caregiver's consent. Caregivers signed an informed consent for the children to go and take the tests.

Camp activities and questionnaires

Educational activities (approximately 3h/day) are designed to improve children's knowledge of epilepsy, importance of taking medication, nutrition, academic choices, employment decisions and driving regulations. These issues were discussed in groups or in one-by-one sessions. Activities included indoor or outdoor supervised swimming, team sports (including tae-kwon do practice), age appropriate outdoor fun activities and games, arts and crafts and entertainment such as disco and movie night.

Clinical psychologists with the help of a neuropediatrician, who are members of the professional education team, created questionnaires and tests who filled out by camp attendees every year at the beginning and at the end of the camp. All materials were reviewed and approved by external experts (clinical psychologist). Each of the participants filled out three questionnaires: 1) General data questionnaire and pre-camp knowledge test; Supplementary Material 1; 2) Camp satisfaction questionnaire and post-camp knowledge test; Supplementary Material 2; 3) Questionnaire on adaptation to epilepsy in young people. Supplementary Material 3.

On the first day of the camp attendees took the General data questionnaire and pre-camp knowledge test; questionnaire including basic information (name, date of birth, grade in school), information about attendance of such camp (whether they attended it before) and information about the duration of the disease. Further 23 questions were multiple choice or fill in the blanks regarding epilepsy with a possibility to add some personal suggestions at the end.

On the last day of the camp attendees took the Camp satisfaction questionnaire and post-camp knowledge test. This test included basic information about the camp's advisor (surname, name) followed by 23 multiple choice or fill in the blanks questions with a possibility for a descriptive opinion

SUPPLEMENTARY MATERIAL 1

HUE

Croatian Association for Epilepsy

Klinika za pedijatriju
Od 1904.

KBC Sestre milosrdnice Zagreb
Pediatric Clinic

Educational and Rehabilitation Camp
General data questionnaire and knowledge test

Name and surname .... Date of birth .... Gender .... Age ....
Class .... I am in camp 1st time 2nd time 3rd time
My illness is ...., and has lasted since my .... years

General information

1. I take my therapy regularly YES Sometimes I forget I don't need therapy anymore
2. There was a period when I should not have taken medication YES NO
3. I have spent my summer without parents YES NO
4. In my school, my illness is known to: a) the class teacher, b) some students, c) no one, d) everyone
5. I had a seizure at school YES NO
6. Holidays with epilepsy worry me a) lot, b) medium, c) little

Knowledge test

1. Epilepsy is a contagious disease YES NO
2. What does the word epilepsy mean ....
3. I can decide for myself when I will take medication and when I will not YES NO
4. What is an aura ....
5. I would be better off not taking medication at all YES NO
6. Due to epilepsy we are not allowed to play video games YES NO
7. Because of medication, I concentrate less at school YES NO
8. Because of my illness, I can't do as much as my peers can
   give an example of what you can't ....
9. What is a grand mal? ....
10. Working at a computer can trigger a seizure YES NO
11. A person with epilepsy can take sports such as peers without epilepsy with medication and control: YES NO
12. What is absence? ....
13. A person with epilepsy must take an antiepileptic for life: YES NO
14. Because of epilepsy you should not dive YES NO
15. Is there a law on driving a person with epilepsy YES NO
16. A person with epilepsy can choose the education / job they want YES NO
17. A person with epilepsy can get married and have children: YES NO
18. I can work at a computer: ....
    ....
    ....
19. I can swim and dive if ....
20. A person with epilepsy with medication and control can live like a peer without epilepsy: YES NO
21. A person with epilepsy can choose education / job according to ability and interest: YES NO

I want to add something: ....
....
....
....
....

SUPPLEMENTARY MATERIAL 2

HUE

Klinika za pedijatriju
Od 1904.

Croatian Association for Epilepsy

KBC Sestre milosrdnice Zagreb
Pediatric Clinic

Educational and Rehabilitation Camp
Questionnaire on satisfaction with the camp and test of knowledge after the camp

Name and surname ....

1. I am glad that I spent 7 days at sea: YES NO
2. My favorite work was: ....
3. It was hard for me ....
4. I had seizures YES NO
5. I had problems with ....
6. The food was ....
7. I heard from my parents a) too much, b) a lot, c) medium, d) little, e) too little
8. Staying in the camp has benefited me – circle the letter next to what applies to you
   a) to meet new friends, b) to recreate sports,
   c) to see how others are with the same disease, d) to have a good time,
   e) to learn something new about the disease, f) to take a break from school
9. I got along with the staff a) very well, b) medium, c) poorly
10. Now I am worried about holidays with epilepsy a) more, b) the same, c) less
11. Now that I know more young people with epilepsy ....
    ....
12. I learned something new about epilepsy: YES NO
13. I want to go to Camp again next year: YES NO
14. Now I know better how to behave and live with epilepsy: YES NO

My opinion about the Camp in a few words: ....
....
....
....
....

Knowledge test (after the camp)

1. Epilepsy is a contagious disease YES NO
2. What does the word epilepsy mean ....
3. I can decide for myself when I will take medication and when I will not YES NO
4. What is an aura ....
5. I would be better off not taking medication at all YES NO
6. Due to epilepsy we are not allowed to play video games YES NO
7. Because of medication, I concentrate less at school YES NO
8. Because of my illness, I can't do as much as my peers can
   give an example of what you can't ....
9. What is a grand mal? ....
10. Working at a computer can trigger a seizure YES NO
11. A person with epilepsy can take sports such as peers without epilepsy with medication and control: YES NO
12. What is absence? ....
13. A person with epilepsy must take an antiepileptic for life: YES NO
14. Because of epilepsy you should not dive YES NO
15. Is there a law on driving a person with epilepsy: YES NO
16. A person with epilepsy can choose the education / job they want YES NO
17. A person with epilepsy can get married and have children: YES NO
18. I can work at a computer: ....
    ....

SUPPLEMENTARY MATERIAL 3

Name and surname: ______________________ Age: ________ Gender: M / F (circle)

How long have you had epilepsy? ______________________________

INSTRUCTIONS: This questionnaire contains 20 statements to assess your attitude towards epilepsy and its impact on your life. There are no "right" or "wrong" answers, because everyone has the right to their own opinion. It would be good not to dwell too long on a particular issue.

For each statement, circle the answer that indicates the extent to which you agree or disagree with the statement.

1.	If I didn't have epilepsy I would be a different person	Not true at all	Not true	I don't know	True	Exactly true
2.	I don't like it when people say I have epilepsy	Not true at all	Not true	I don't know	True	Exactly true
3.	Epilepsy is the worst thing that has happened to me in my life	Not true at all	Not true	I don't know	True	Exactly true
4.	Most people would find it difficult to adjust to having epilepsy	Not true at all	Not true	I don't know	True	Exactly true
5.	I am often embarrassed because I have epilepsy	Not true at all	Not true	I don't know	True	Exactly true
6.	There is not much I can do to control epilepsy	Not true at all	Not true	I don't know	True	Exactly true
7.	With epilepsy, one cannot have a normal life	Not true at all	Not true	I don't know	True	Exactly true
8.	Medications for epilepsy are harmful	Not at all true	Not true	I don't know	True	Exactly true
9.	I try not to let others know that I have epilepsy	Not true at all	Not true	I don't know	True	Exactly true
10.	When someone is told they have epilepsy, it's like being sentenced to an illness for the rest of their lives	Not true at all	Not true	I don't know	True	Exactly true
11.	Epilepsy has ruined my social life	Not true at all	Not true	I don't know	True	Exactly true
12.	Because of epilepsy, some do not want to hang out (play) with me	Not true at all	Not true	I don't know	True	Exactly true
13.	People don't understand what it's like to have epilepsy	Not true at all	Not true	I don't know	True	Exactly true
14.	Perennial epilepsy changes a person	Not true at all	Not true	I don't know	True	Exactly true
15.	Epilepsy is a serious and dangerous disease	Not true at all	Not true	I don't know	True	Exactly true
16.	Epilepsy is a big problem even if you don't have seizures	Not true at all	Not true	I don't know	True	Exactly true
17.	When you have epilepsy, there is nothing you can do to make it better	Not true at all	Not true	I don't know	True	Exactly true
18.	There is no one with whom I can talk openly about epilepsy	.Not true at all	Not true	I don't know	True	Exactly true
19.	With epilepsy, everything can be done as when you are healthy	Not true at all	Not true	I don't know	True	Exactly true
20.	I often think how unfair it is for me to have epilepsy while others are so healthy	Not true at all	Not true	I don't know	True	Exactly true

about the camp for each attendees. The questionnaire consists of 20 Likert-type statements, to assess attitudes about epilepsy and its impact on respondents' lives.

All of the attendees also filled the Questionnaire on adaptation to epilepsy in young that consists of 20 statements to assess the state of their illness and its impact on the quality of life. This questionnaire was answered during a psychological workshop in the camp. The task of the attendees was to assess, on a scale of 5 degrees, to what extent they agree with the statement. The questionnaire was designed for the

TABLE 1. **Results of Adaptation to Life with Epilepsy Questionnaire**

	Not at all	Not true	Do not know	True	It's entirely true
	N (%)	N (%)	N (%)	N (%)	N (%)
If I had no epilepsy, I would be a different person.	10,5	21,1	39,5	26,3	2,6
I do not like when it is said that I have epilepsy.	10,5	23,7	5,3	50	10,5
Epilepsy is the worst thing in my life.	28,9	31,6	15,8	18,4	5,3
Most people would find it difficult to adjust to epilepsy.	/	18,4	55,3	21,1	5,3
I'm often uncomfortable because I have epilepsy.	18,4	31,6	2,6	39,5	7,9
I do not want others to find out that I have epilepsy.	5,3	55,3	2,6	36,8	/
When someone says that he has epilepsy, as if he is condemned to illness for the rest of his life.	39,5	47,7	5,3	7,9	/
People do not understand how it is to have epilepsy.	/	23,7	26,3	36,8	13,2
There is no one with whom you can talk openly about epilepsy.	47,4	47,4	2,6	2,6	/
I often think it is unjust to have epilepsy while others are so healthy.	10,5	23,7	5,3	50	10,5
Epilepsy spoiled my social life.	23,7	34,2	10,5	21,1	10,5
Because of epilepsy some do not want to play with me.	23,7	18,4	7,9	39,5	10,5
There is not much I can do to control epilepsy.	5,3	39,5	15,8	31,6	7.9
With epilepsy I cannot have normal life.	34,2	23,7	13,2	23,7	5,3
Epilepsy drugs are harmful.	15,8	13,2	55,3	15,8	/
Long-term duration of epilepsy change personality of a person.	/	7,9	42,1	39,5	10,5
Epilepsy is a serious and dangerous disease.	10,5	55,3	31,6	2,6	/
Epilepsy is quite a big problem even if you do not have seizures.	5,3	13,2	13,2	65,8	2,6
When you have epilepsy you cannot do anything to make it better.	10,5	55,3	23,7	10,5	/
With epilepsy everything can work as if you are healthy.	5,3	21,1	26,3	36,8	10,5

purpose of research in order to improve the quality of life and their skills in the areas of social interaction.

Statistical analysis

Gathered data was processed using the SPSS 16.0 statistical package. Qualitative data are presented in absolute and relative frequencies (N, %). Descriptive statistics of each individual variable were prepared. The pattern was divided into samples according to the research question being examined. Since these were categorical variables, a t-test on the independence of features in the contingency table was used, which checks the statistical significance of the difference in the frequency of certain answers to a particular question. The results of the quantitative data analysis were interpreted with at least a 5% level of significance.

RESULTS

The median age of children in the camp was 13 years and 9 months (range 6 years to 18 years). There were more female 103,5 (64.7 %) than male 56,5 (35.3%) for 8 years. Every year there were 8,2 (41.2%) of new attendees in the camp and 11,8 (58.8%) of attendees who have participated in the camp two or more times. The median duration since epilepsy onset was from 1year to 14 years (median 6.93 years). Regarding descriptive data, 76,5% of children knew that they had epilepsy. In 10% of children, friends and distant family members did not know about the epilepsy diagnosis. Before establishing good control of epilepsy, 42.1% of children had a convulsive seizure at school and 57.9% had no seizure at school. During the camp only 7.9% had epileptic seizure. More than half of the participants (55.3%) had previously been on holidays without parents.

Analysing the results of the pre-camp and post-camp knowledge test about epilepsy that was given at the beginning of the camp and after the education was completed, the average percentage of correctly solved questions rose from 65% to 87% after education ($t = -6.981$, $p < 0.01$). Children who participated in the camp two times were also involved in solving both epilepsy knowledge tests.

The results of Questionnaire on adaptation to epilepsy in young people is showed in Table 1. The following results can be extracted from the table: the statement 1; "If I didn't have epilepsy, I would be a different person" the largest number of respondents, 39.5% answered that they "don't know". The statement "I don't like it when people say I have epilepsy" is true by 50% of respondents, while 10.5% of them think the statement is completely true. In claim 4; the largest number of respondents 55.3% answered that they do not know the answer; "It would be difficult for most people to adjust to having epilepsy." To statement 10 "I often think how unfair it is for me to have epilepsy while others are so healthy", 50.0% answered that it was "true", and statement 12; "Because of epilepsy, some do not want to hang out (play) with me", the largest number of respondents 39.5% believe correct. Claim 15 "Epilepsy drugs are harmful", 55.3% of respondents do not know the answer. The largest number of respondents 65.8% answered "correctly" to statement 18 "Epilepsy is a big problem even if you do not have seizures", while 55.3% answered "is not true" to the statement "When you have epilepsy there is nothing you can do to get better". Finally, 36.8% and 10.5% of respondents consider the statement "With epilepsy, you can do everything as if you are healthy" correct and completely correct.

DISCUSSION

To our knowledge, this is the first study to show the results of the level of knowledge about epilepsy as a disease in children and how epileptic camps affect the daily lives of children with epilepsy. In our camp did the children fill in the epilepsy pre- and post- knowledge test, as well as the evaluation of the success of the educational-rehabilitation camp at the end. The average percentage of correctly solved tasks in the first test was 65%, and in the latter 87%. The analyses of surveys and tests showed that only 75% of children in camp knew that they had epilepsy. In 10% of children, friends and distant family members did not know about epilepsy. The answers in the questionnaire on adaptation to life with epilepsy are indicators of strong stigma in children with epilepsy. Each year at least one child had a seizure during the camp. Since we did not find that other or similar epilepsy questionnaires were filled out in other camps, we could not compare this data.

Epilepsy camp is a place for fun as well as a place where children attending the camp get the knowledge about epilepsy and feel supported (11). Educational and rehabilitation camps for children with chronic illnesses have been organized in Zagreb for many years, while the project "Improving the life of children and adolescents suffering from epilepsy" including an educational and rehabilitation camp for children with epilepsy started for the first time in 2010, with only one camp per year, under the auspices of the City Health Office of the City of Zagreb. This educational and recreational camp for children with epilepsy has been organized during summer or winter holidays. In the world, camps for children with epilepsy and other chronic illnesses are also organized during holidays. The first organized camp for children with chronic illnesses including epilepsy was in the summer of 1998 at the Covenant Heights National Park, Estes Park, Colorado (12). In addition to this camp, there are many summer camps for children with epilepsy in the United States and Canada. (13, 14, 15, 16).

Gender and age of participants in Croatian epilepsy camp were similar in all years. The children in the camp were between 6 and 18 years old, matching the data of other camps in the world (14). In our camp, as well as in the mentioned camps of children with epilepsy in the United States, parents were not present (13).

It was particularly important for us to see that our camp has an educative character as it was intended as an educational rehabilitation camp, which means that there were education workshops on epilepsy and life with epilepsy (4 workshops with a child neurologist and 4 workshops with a clinical psychologist).

Searching the published literature, we did not find similar educational epilepsy camps for children offering better understanding of the disease and also targeted to fight the stigma with structured activities helping children to understand that they are not alone with their problems and that they can live a life as their healthy peers.

We did not compare the differences of the social interactions (11) for every year as *Cushner-Weinstein* et al. did in their study where they compared 3 years and results showed significant improvement in all examined segments (social interaction, active participation, responsibility and communication) in the year 3 (12). We showed differences in the knowledge between the first day and the last day of stay in the camp According to the answers to the questionnaire on epilepsy life adaptation, it is also seen that the stigma is very pronounced in children with epilepsy: On one of the claims – I do not like when I'm told that I have epilepsy, 60.5% of respondents agree that the statement is true. Also 47.4% feel discomfort because they have epilepsy. Half of the respondents think it is unfair to have epilepsy while others are so healthy. In the literature, we could not find similar data about adaptation to life with epilepsy to compare with our data even though we think this would be important because it could contribute to a better understanding of life with epilepsy (20).

These data encouraged us to establish the Committee for Preservation and Improvement of Quality of Life of People with Epilepsy and based on it, continuous education on epilepsy for all kindergarten, elementary and high school teachers of the City of Zagreb was established within the City Health Office, and was conducted during 2015/16. According to the searched literature, no identical data were found on teacher education in other countries. The same results are if you compare to the other disease (21, 22).

When observing the results, it should be taken into account that the research was conducted on an appropriate sample and as such a sample of respondents cannot be considered representative, given that 5.5% of children under 18 in Croatia have active epilepsy (23). It is important to mention the limitations of some of the questions, given the large age range in children of camp participants who ranged from 8 to 18. Older respondents have more knowledge and experience about their disease, seizures and treatment than younger children. The limitation of the research is limited by the inclusion of a larger number of children in the camp of children with epilepsy and accompanying medical staff, and the number of both depends on the financial resources received.

CONCLUSION

The results show that the camp for children with epilepsy can improve knowledge, socialization and communication among children with epilepsy.

The main message of the camp was for children to be confident that they can reach their full potential in life and to feel equal to their peers in every aspect of life. All children were continuously encouraged to improve their knowledge of epilepsy and associated lifestyle modifications to ensure good health. A specific camp designed for children with epilepsy can improve adaptive behaviours and social interactions. Participants enjoyed the experience and received education in a supportive environment.

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SAŽETAK

Korisnost kampa za djecu s epilepsijom: retrospektiva

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Cilj: Cilj ovog istraživanja bio je procijeniti dobrobiti obrazovnih i rekreacijskih programa kampiranja za djecu s epilepsijom.

Metoda: Proveden je retrospektivni pregled podataka prikupljenih od sve djece koja su pohađala godišnje kampove za epilepsiju u organizaciji Hrvatske udruge za epilepsiju i Gradskog ureda za zdravstvo Grada Zagreba tijekom 8 godina. Uključena su djeca u dobi od 6 do 18 godina. Osoblje kampa uključuje dječje neurologe, psihologe, neurološke medicinske sestre i educirane volontere. Edukativne aktivnosti osmišljene su kako bi poboljšale znanje djece o epilepsiji, važnosti uzimanja lijekova, akademskim izborima, predloženom zaposlenju i propisima koji se odnose na zakone o vožnji. O tim pitanjima raspravljalo se u skupinama ili u pojedinačnim sesijama, ovisno o slučaju. Ostale aktivnosti uključivale su plivanje pod nadzorom, timske sportove, zabavne aktivnosti i igre, umjetnost i rukotvorine te zabavu poput diska ili filmske večeri.

Svaki od sudionika ispunio je tri upitnika 1. Upitnik s općim podacima i provjeru znanja prije kampa; 2. Upitnik o zadovoljstvu kampom i provjera znanja nakon kampa; 3. Upitnik o prilagodbi na epilepsiju u mladih.

Rezultati: Analize anketa i testova pokazuju da je samo 75% djece u kampu znalo da boluje od epilepsije. U 10% djece prijatelji i dalji članovi obitelji nisu znali za epilepsiju. Uspoređujući provjeru znanja prije i nakon kampa, prosječan postotak točno riješenih zadataka na prvom testu je 65%, a na drugom 87%. Odgovori u upitniku o prilagodbi na život s epilepsijom pokazatelji su jake stigme kod djece s epilepsijom.

Zaključci: Glavno postignuće kampa bilo je da djeca steknu samopouzdanje da mogu ostvariti svoj puni potencijal u životu i da se osjećaju ravnopravno sa svojim vršnjacima u svakom aspektu života.

Ključne riječi: EPILEPSIJA; KVALITETA ŽIVOTA; ADAPTIVNO PONAŠANJE; REKREACIJSKA TERAPIJA