

COPING SKILLS IN CHILDREN WITH EPILEPSY – EVALUATION OF COGNITIVE BEHAVIORAL THERAPY INTERVENTION

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SUMMARY – A pilot study was conducted to examine the efficiency and satisfaction of cognitive behavioral therapy (CBT) intervention in youth with epilepsy regarding coping strategies. The CBT intervention was based on the main principles and empirically supported cognitive-behavioral techniques. The intervention consists of epilepsy education, stress education, and coping skill strategies. Seventeen children and adolescents aged 9-17 diagnosed with epilepsy for at least one year, with at least average intelligence and no history of serious mental illness completed the CBT intervention during summer camp, providing data on the efficiency of and satisfaction with CBT intervention. Upon completion of the CBT intervention, study subjects achieved significantly higher scores on the following Scale of Coping with Stress subscales: Problem solving; Seeking for social support from friends; Seeking for social support from family; and Cognitive restructuring, for both measures of usage frequency and effectiveness of each subscale. The participants reported a high level of satisfaction with the CBT intervention. This study provided explanation of research limitations and recommendations for future clinical trials.

Key words: *Epilepsy psychology; Child; Stress, psychological; Adaptation, psychological; Cognitive therapy – methods; Chronic disease*

Introduction

It is well known that children and youth with epilepsy have poorer psychosocial adjustment, lower quality of life, and higher incidence of psychiatric problems in comparison to their peers¹⁻⁶. Even though direct consequences of illness (e.g., unpredictable epileptic seizures, long-term medication therapy, different restrictions, and necessary safety precautions) undoubtedly have negative effects on everyday functioning of persons with epilepsy⁷, studies show that stereotypes and discrimination can cause a substantial

amount of distress and that patients suffering from this illness actually perceive them as a bigger burden than experiencing epileptic seizures⁸⁻¹⁰. This is supported by data which show that children and youth with epilepsy have a lower health-related quality of life, even when they do not have active epileptic seizures¹¹. In addition, they have a significantly lower quality of life in general and more psychosocial problems compared not only to other youth, but also to youth with chronic illness such as asthma and diabetes^{1,3,12,13}.

Children and youth with epilepsy are confronted with many intensive stressors like fear from having epileptic attacks, feelings of stigmatization^{9,14,15}, and peer relationship problems¹⁶. At the same time, they have less effective coping strategies to deal with stress compared to general population¹⁷. This problem becomes even bigger if we take into account that, according to

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patient self-reports, stress is one of the most common precipitating factors for epileptic seizures¹⁸⁻²².

Research data indicate that coping strategies have significant impact on psychosocial outcomes of patients with epilepsy and that psychosocial support should be an integral part of the treatment, especially for younger patients who are still in the process of development and are confronted with a lot of challenges while growing up. The benefits of strategies directed to active problem solving and searching for social support are especially prominent^{10,17,23}. That is why recent approaches to patients with epilepsy include focusing on coping strategies and patient perception of their illness²³. According to Smeets *et al.*²⁴, improving self-efficacy and coping skills can contribute to better adjustment to epilepsy, better social status and better employment opportunities. Cognitive-behavioral approach has been documented as an efficient and commonly used method for improving a variety of important psychosocial outcomes in children and youth with chronic illnesses including epilepsy²⁵⁻²⁸.

The aim of this study was to explore the efficiency of short cognitive-behavioral therapy (CBT) intervention regarding coping strategies, which was conducted during 8-day camping for youth and children with epilepsy, offering additional implications for clinical practice.

Subjects and Methods

Intervention development

Development of CBT intervention aimed at increasing coping skills in children and youth with epilepsy started with thorough review of the literature. Two psychologists with expertise in pediatric, clinical and health psychology and having participated in summer camp created CBT intervention for increasing coping skills in children and youth with epilepsy.

One of the experts was involved in CBT education and had experience in clinical work with children and youth with epilepsy. External expert (clinical psychologist) provided constructive feedback on the psycho-educative workshops created and helped with final revision of the intervention.

The contents of CBT intervention was divided in two parts: psycho-educative part aimed at increasing coping skills (led by two psychologists) and educative part addressed the symptoms of epilepsy (led by two neuropsychiatrists). The program was structured into modules, which were designed to be interactive, educative and stimulating. Trainers were actively engaging all participants and encouraging them to contribute with their comments or questions. Detailed manuals for trainers were prepared to ensure adherence to the planned design of workshops. Workbook was administered to every participant, and during workshops colorful PowerPoint presentations were projected as side material. All materials were reviewed and approved by external expert (clinical psychologist).

Module contents

Part of the intervention focused on education on epilepsy symptoms had three modules (Table 1), as well as the part focused on increasing coping skills (Table 2). The main goals of CBT intervention were as follows:

- to inform participants about possible coping strategies
- to promote use of more appropriate coping strategies
- to decrease distress and discomfort that participants experience because of their illness
- to encourage sharing experiences and social interactions in the group
- to educate participants about epilepsy and how to improve their quality of life

Table 1. Epilepsy education modules

	Title	Contents and goals
1	Epilepsy in general	Definition and types of epilepsy; causes of epilepsy
2	Epilepsy and me	Medications; factors that affect seizures, treatments
3	Epilepsy and quality of life	Quality of life with epilepsy; epilepsy and videogames; epilepsy and sports; epilepsy and school; epilepsy and driving license; epilepsy and pregnancy

Subjects

The study sample included 17 children and youth with epilepsy, who were participating in the psycho-educative recreational summer camp in 2013. Camp participants (11 girls and 6 boys) were chosen by three neuropediatric teams from different pediatric departments in Zagreb, Croatia. Their age range was 9-17, mean age 13.4 years. All participants were diagnosed with epilepsy according to ICD-10, had epilepsy for at least one year (average length of illness was 6 years), had no serious psychiatric illness and were regularly followed-up by a pediatrician. All participants in the camp regularly took prescribed medication, except for two children (in accordance with the recommendation of the neuropediatrician).

Most of the children and youth had previous experience of participating in a camp, but with different educational contents. All of them were staying in camp without their parents and, according to self-reports, they were not worried because of it. All participants were adjusted to staying in the camp without parents. None of them had epileptic seizure during their stay in the camp and there were no dropouts from the camp or workshops. Most of the children and youth had average cognitive capacity (according

to their medical records), except for two participants whose cognitive capacity was below average. For these two participants, additional assistance in workshops was provided by psychologist, in order to ensure that they could follow properly the contents of the modules.

Instruments

To assess the efficiency of short CBT intervention, two knowledge tests, one scale and one questionnaire were used. All responses were anonymous and parents gave permission for participation of their children in the study.

The Scale of Coping with Stress (SUO) coping scale for children and adolescents²⁹ was used to assess different coping strategies before and after intervention³⁰. It is intended for children aged 9-18 years, both for individual and group application. Approximate time for solving is 20 minutes. The scale measures the frequency of usage and the perceived efficiency of different coping strategies. With adjustment of instructions, it can be used for measuring both dispositional and situational coping strategies. The scale is composed of seven subscales, which describe different coping strategies: Problem solving (9 items); Cognitive

Table 2. Education modules for stress and coping skill strategies

	Title	Contents and goals
1	Stress	<ul style="list-style-type: none"> • Defining stress and understanding how it is caused • Recognizing symptoms of stress • Understanding effects of stress on the entire body: thoughts, behavior, physical reactions and emotions • Introduction to coping strategies
2	Coping	<ul style="list-style-type: none"> • Sharing experiences about stressful events • Becoming aware that stress is part of everyday living and how important it is to learn how to cope appropriately • Explaining different coping strategies (primary and secondary coping skills) • Recognizing there are different possible responses to the same situation (behavior change) • Changing thoughts (cognitive restructuring)
3	How to cope with different emotional challenges related to epilepsy?	<ul style="list-style-type: none"> • Using creative ways to define and elaborate problems (problem solving) • Recognizing that different coping strategies are appropriate in different situations • Summarizing and synthesizing new skills and knowledge • Sharing new insights and ideas how to apply knowledge in everyday life

restructuring (8 items); Emotional reactivity (8 items); Distraction (10 items); Avoidance (11 items); Seeking for social support from friends (6 items); and Seeking for social support from family (6 items). When solving, participants mark usage frequency and perceived efficiency for each item on a 4-point Likert scale. Examples of items: „I think about how my parents will comfort me“; „I think about something else to forget the problem“; „I try to solve problem in my head like puzzle“; „I listen to the music or write“, etc. Reliability and validity of the SUO have been established²⁹. The SUO demonstrates a replicable factor structure, stability over time, and very good reliability and validity. Before CBT intervention, participants solved the coping scale (SUO) with the instruction to estimate the usual usage frequency and perceived efficiency of every item. Immediately after CBT intervention, participants solved the same scale, but the instruction was modified, with permission of the author of the scale. On retesting, participants were told to estimate how likely they would use different strategies in the future, in hypothetical situations, and how efficient they thought they would be.

Two knowledge tests were constructed for the purpose of this study, one about epilepsy in general, and the other one about epilepsy and coping. Both tests had open and closed question types. Knowledge test about epilepsy had 21 questions in total (e.g., „What is absence seizure?“, „Can work on computer cause seizure?“, „Can I decide for myself whether to take medications or not?“). Knowledge test about stress and coping skills had 16 questions in total (e.g., „What is stress?“, „Do all people experience stress?“, „What are the most common physical reactions to stress?“, „List all mind-traps that you know?“).

Finally, participants filled in the questionnaire assessing their satisfaction with the camp in general and with the workshops. The questionnaire had 14 questions and 5 statements rated on a 5-point Likert scale (e.g., „It was exhausting“; „I learned something new about epilepsy“; „I liked participating in workshops“).

Procedure

Summer camp for children and youth with epilepsy was organized in 2013 by the Croatian Epilepsy Society in cooperation with Clinical Department of Pediatrics, Sestre milosrdnice University Hospital Center,

with the City of Zagreb sponsorship. Participation in the camp was free of charge for all participants. During the 8-day camp, all children were out of their place of residence, without parents, so the team of experts took care of them. The team was composed of two neuropsychiatrists, one pediatrician, two psychologists (one psychologist on education for cognitive-behavior therapist and one intern), two nurses and two animators. The camp included educative workshops (epilepsy and coping), fun activities (different games, performances) and recreational activities (going to beach, swimming, walks, and excursions).

The CBT intervention comprised six modules, three focused on education about epilepsy and three focused on coping strategies. Workshops were held daily, in the morning, for a period of 90 minutes. Modules about epilepsy were led by neuropsychiatrists in cooperation with pediatric psychologist, and modules about coping strategies were led by two psychologists (one pediatric psychologist on education for cognitive-behavior therapist and one intern from pediatric department). Different activities like role plays, problem solving techniques, presentations and behavioral rehearsals were included in the workshops to enhance interaction and active learning. Various work materials were prepared for every participant (workbook, handouts, creative materials, etc.). Every workshop was followed by small prize giving, and at the end of the modules, symbolic presents were given to participants. The SUO coping scale and two knowledge tests (one on epilepsy in general and one about coping strategies) were applied before and after CBT intervention, whereas the satisfaction questionnaire was applied after CBT intervention.

Statistical analysis

Data analysis for this study was descriptive. For testing the normality of sample distribution we used Shapiro-Wilk test for small samples. Pre- and post-program results were compared by Wilcoxon signed rank test for nonparametric samples. The IBM SPSS.20 software was used on statistical data processing.

Results

Seventeen children diagnosed with epilepsy, six male and 11 female, mean age 13.4 (age range 9-17)

Table 3. Assessment of the frequencies and effectiveness of using different coping strategies before and after cognitive behavioral therapy (CBT) intervention

Before CBT intervention	RP f	RP e	IZ f	IZ e	ER f	ER e	PP f	PP e	PO F	PO e	KR f	KR e	DI f	DI e
Raw score	13	14	13	14	7	6	8	9	8	10	8	10	13	16
Decile	3	3	5	5	5	5	4	3	4	4	3	3	5	6
After CBT intervention	RP f	RP e	IZ f	IZ e	ER f	ER e	PP f	PP e	PO F	PO e	KR f	KR e	DI f	DI e
Raw score	16	18	13	16	6	6	10	12	9	11	11	14	16	18
Decile	4	5	5	5	5	5	5	5	5	5	5	5	7	7

f = frequency; e = efficiency; RP = problem solving; IZ = avoidance; ER = emotional reactivity; PP = seeking help from friends; PO = seeking help from family; KR = cognitive restructuring; DI = distraction

years, were included in the study. The average duration of illness was 6 years. All enrolled participants completed the study.

The mean score for the epilepsy knowledge quiz (21-item quiz) before CBT intervention was $M=11.59$. After the program, the mean score on knowledge quiz was $M=16.29$, which was significantly higher than the score before the intervention ($t=3.45$, $p<0.01$).

Also, participants scored significantly higher results on 16-item quiz on stress knowledge and coping with stress after CBT intervention as compared with the result before the intervention ($t=3.62$, $p<0.01$). The mean score was $M=6.32$ and $M=14.15$ before and after the intervention, respectively.

Before CBT intervention, the least frequently used and the least effective coping strategies on the SUO were Problem solving and Cognitive restructuring, while Distraction was estimated as the most effective and the most frequently used strategy. Following participation in the short CBT intervention, ratings of the frequency and effectiveness of coping strategies mainly increased and Distraction was still rated as the most frequently used and most effective coping strategy (Table 3). After CBT intervention, participants achieved a significantly higher score in SUO (both in usage frequency and effectiveness) on the following subscales: Problem solving; Seeking for social support from friends; Seeking for social support from family; and Cognitive restructuring (Table 4).

Immediately after CBT intervention, participants completed the questionnaire aiming to assess their satisfaction with participation in the camp and workshops. The results showed that 100% of the children

found their stay in the camp and participating in the modules helpful. Most of the children (64.7%) were less concerned about spending the summer without their parents. Participating in the camp had multiple benefits for the children; most of the children improved their knowledge about epilepsy, and met other children with the same illness. Meeting others with epilepsy helped most of the children feel accepted and safe; 94% of the children reported that after the camp,

Table 4. Hypothesis test summary – related-samples Wilcoxon signed rank test in different coping strategies before and after cognitive behavioral therapy (CBT) intervention

Coping strategy – variable	Level of significance
Problem solving – f	0.009**
Problem solving – e	0.002**
Avoidance – f	0.622
Avoidance – e	0.334
Emotional reactivity – f	0.568
Emotional reactivity – e	0.793
Seeking help from friends – f	0.020*
Seeking help from friends – e	0.006**
Seeking help from family – f	0.004**
Seeking help from family – e	0.022*
Cognitive restructuring – f	0.026*
Cognitive restructuring – e	0.023*
Distraction – f	0.073
Distraction – e	0.151

f = frequency; e = efficiency; * $p<0.01$; ** $p<0.05$

they knew much more about epilepsy and how to cope with stress, while 88.2% of the children expressed their desire to return to the camp next year.

Discussion

Results from this study showed positive effects of CBT intervention on the children's knowledge about epilepsy and stress, as well as on their coping with stress. After completion of the modules, the children's knowledge about stress and coping strategies significantly improved, as well as their knowledge about epilepsy, where the mean score even doubled compared to the mean score before the modules. Such a result is consistent with similar studies which also report an increase in knowledge (about epilepsy and seizures) after conduction of different interventions^{28,31,32}. These results suggest that the implemented modules significantly influenced the increase of knowledge about epilepsy in children, and their knowledge about stress and coping strategies. The importance of this finding lies in logical conclusion that knowledge about stress and possible coping strategies contributes to their coping with stress successfully.

Analysis of the participants' results on SUO revealed that after CBT intervention, children estimated that they would more frequently use most of the coping strategies and that these strategies would be more efficient for them. In other words, it can be assumed that the intervention had positive effect on expansion and diversity of the possible coping strategies with stress, as well as on their estimate that different coping strategies are generally more helpful, especially for the following coping strategies: Problem solving; Seeking for social support from friends; Seeking for social support from family; and Cognitive restructuring. As mentioned in the Introduction section, it is generally considered and stated through numerous studies that active coping strategies (i.e. problem-focused coping and seeking social support) are more efficient compared to other coping strategies^{33,34}.

On the other hand, before the CBT intervention, the most commonly used strategies were Avoidance; Expressing feelings; and Distraction. It is not surprising considering that children with epilepsy probably perceive illness as an uncontrollable state in which emotion-focused coping strategies are more common-

ly used. Although it has been stated that active coping, such as problem solving and cognitive restructuring, is associated with better psychological adjustment, there are some authors who do not share this opinion. The context of coping and the nature of stressor should be taken in consideration, having in mind controllability of stressful circumstances (whether or not they are controllable) and adjusting the specific coping strategy accordingly. Therefore, efficiency of the coping strategy used depends on the perception of stressful situation and on the evaluation of one's own coping style^{33,34}.

The results should also be considered in the light of coping characteristics specific for children and adolescents. The degree of the child's cognitive and social development affects the selection and repertoire of coping strategies. Thus, for example, problem solving method develops around middle childhood with the development of complex cognitive abilities, whereas for younger children it is characteristic that they experiment with a greater number of coping strategies compared to adolescents who use a smaller number of proven strategies^{30,33}. The results concerning the coping strategy Seeking for social support were also expected since children more than adults depend on the others and in general on their environment due to the lower capacity of personal resources³⁴, and thus it is important for them to use 'available' coping strategies.

Weaknesses of the study should also be mentioned. First limitation refers to measurement of the usage frequency and effectiveness of coping strategies upon completion of CBT intervention. The participants were asked to estimate how often they would use different coping strategies in the future and how efficient they would be for them. However, it is not possible to know whether it will really be so. Furthermore, the sample size was small and may not represent the general pediatric epilepsy population. There was no control group, so we cannot be completely sure whether the results could be attributed to the CBT intervention itself. There is no proof that the CBT itself was the major factor for the positive changes reported. It is feasible that young people with epilepsy who meet other young people with the same condition might greatly improve in both their attitude and coping strategies. Also, parents were not included in the study. There was no follow up to provide informa-

tion on whether the CBT intervention had long-term effects. Future studies should include control group to make sure that CBT intervention itself affected changes on post-examination.

Conclusion

Study results supported the efficiency of short CBT intervention on increase of the knowledge about epilepsy and stress, as well as on diversity of the possible use of coping strategies. Taking into account recommendations from the current literature on the application of interventions aimed at enhancing coping skills as an effective treatment for pediatric epilepsy³⁵, it is concluded that this CBT intervention was effective given both the overall increase in the usage of different coping strategies and increase in the usage frequency and effectiveness for Problem solving strategy; Seeking for social support from friends; Seeking for social support from family; and Cognitive restructuring. The application of short and cost-effective intervention yielded positive results, suggesting that short CBT psycho-educational interventions could be beneficial in the treatment of pediatric epilepsy. The mentioned limitations should be taken in consideration when developing further interventions and evaluation studies.

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Sažetak

SUOČAVANJE SA STRESOM U DJECE S EPILEPSIJOM – EVALUACIJA KOGNITIVNO-BIHEVIORALNE INTERVENCIJE

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U ovom istraživanju ispitivala se učinkovitost i zadovoljstvo kognitivno-bihevioralnom terapijom (KBT) za strategije suočavanja sa stresom kod djece i adolescenata s epilepsijom. Provedena intervencija KBT temelji se na osnovnim postulatima znanstveno utemeljene KBT. Intervencija se sastojala od edukativnih radionica o epilepsiji kao bolesti, stresu te o strategijama suočavanja sa stresom. Sveukupno 17 djece i adolescenata u dobi 9-17 godina, prosječnih kognitivnih sposobnosti, s dijagnosticiranom epilepsijom najmanje godinu dana te bez komorbiditeta psihičkih bolesti bilo je uključeno u intervenciju KBT tijekom ljetnog kampa. Nakon završetka intervencije KBT na Ljestvici suočavanja sa stresom za djecu i adolescente ispitanici su postigli značajno bolje rezultate na sljedećim podljestvicama: Rješavanje problema, Traženje socijalne podrške od prijatelja, Traženje socijalne podrške od obitelji te Kognitivno restrukturiranje, i to za obje mjere: frekvencija i učinkovitost svake spomenute podljestvice. Ispitanici su potvrdili visoko zadovoljstvo provedenom kognitivno-bihevioralnom intervencijom. Konačno, provedeno istraživanje definiralo je ograničenja u provedenom istraživanju te dalo smjernice i preporuke za slična buduća klinička ispitivanja.

Ključne riječi: Epilepsija, psihologija; Dijete; Stres, psihološki; Adaptacija, psihološka; Kognitivna terapija – metode; Kronična bolest