# Evaluation of a self-regulation based psycho-educational pilot intervention targeting children and adolescents with epilepsy in Greece

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ABSTRACT

Purpose: The purpose of this study is to describe the development and initial evaluation of a minimal structured psycho-educational intervention for children and adolescents with epilepsy. The intervention aimed at increasing the understanding and personal control (self-management) of epilepsy, and at reducing psychological distress, sleep problems and somatic complaints.
Method: Twelve patients participated in our intervention and another 12, matched on age and gender, served as the control group. Data were obtained at baseline (prior to the intervention) and 3 months later in the context of an interview based on several validated questionnaires. The intervention was limited to one 4-h session using Cognitive Behavioural Therapy techniques, relaxation techniques, video and storytelling. Effects of the intervention on primary and secondary outcomes were examined using 2 (baseline, T1 vs. post-treatment, T2) $\times$ 2 (intervention vs. control) mixed model repeated measures analysis of covariance (ANCOVA), controlling for epilepsy severity.
Results: The analysis revealed that over the three months of the study, significant main effects (group x time) were observed on coherence ($F_{(1,21)} = 6.12$; $p = 0.02$) with important changes in favour of the intervention group. Significant main effects were also observed on psychological distress levels ($F_{(1,21)} = 10.08$; $p = 0.005$) and sleep problems ($F_{(1,21)} = 11.40$; $p = 0.003$).
Conclusion: The results of this study show that a brief self-regulation-based intervention may have beneficial effects for children and adolescents suffering from epilepsy by inciting improvements in coherence, psychological distress and sleep problems.

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## 1. Introduction

The literature suggests that interventions focusing on changing illness appraisals of young individuals as well as enhancing coping skills may be an effective treatment for pediatric psychosocial maladjustment [1–4]. This is especially true for children and adolescents with epilepsy. Epilepsy is amongst the most prevalent neurological diseases, with a substantial negative impact not only on the physical, but also on the cognitive, social, emotional, and behavioural functioning of the patient. As a consequence, several publications point at the necessity of more specific and individualized psycho-educational interventions for children and adolescents [5–9].

In adults with epilepsy several studies have demonstrated that misinformation, poor knowledge about the disease and erroneous beliefs may lead to severe medical and psychosocial consequences, including misuse of anti-epileptic medication, dangerous first aid practices, unnecessary restrictions on daily life, depression, and social withdrawal [1]. For these reasons, educational programs, such as MOSES (Modulares Schulungsprogramm Epilepsie [Modular Educational Epilepsy Program]), have been developed and are part of the standard epilepsy care in German speaking countries [10]. Existing data suggest that patients profit from such programs in many respects [10,11].

For children and adolescents with epilepsy structured psycho-educational programs are equally indicated. Intervention programs

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targeting adolescents with epilepsy have been proven to be effective in increasing knowledge about epilepsy, reducing fear of seizures, and improving self-management practices and medication compliance [4,8,9,12–14]. Understandably, most interventions focus on seizure control rather than on the empowerment of adolescents aiming at increasing personal control over the illness and/or at the reduction of psychological distress, sleep problems or somatic complaints. Lack of control, psychological and somatic complaints result, however, frequently in a lowered quality of life [2,3,15–19].

The aim of the present study is to describe the development and initial evaluation of a minimal structured psycho-educational intervention for children and adolescents with epilepsy. The intervention aimed at a) increasing the understanding (identity and coherence) and personal control of epilepsy, and b) reducing psychological distress, sleep problems and somatic complaints.

Leventhal's Self-Regulation Theory served as the theoretical framework for the construction of the present psycho-educational program. This theory particularly focuses on the effect of illness perceptions and beliefs on illness behavior and the experience of symptoms. According to this theory, important attributes of illness perceptions are: *identity* (the name or label given to the illness or symptoms), *timeline* (the perceived time trajectory of the illness), *consequences* (the expected future effects and outcomes of the illness), *cause* (the supposed etiology of the illness) and *cure or control* (the extent to which the patients believe that they may recover or have personal control over the illness). Finally, *emotional representations of the illness* incorporate anticipated negative emotional reactions such as anger, fear, and distress due to the presence of the disease [15,20–22]. As people with a chronic illness obtain information about their condition and evaluate their attempts to moderate, cure or cope with its effects, new illness representations are formed and developed based upon these experiences [23,24].

## 2. Methods

### 2.1. Participants and procedure

The protocol for the present intervention study was approved by the Ethical Research Committee of Pendeli's Children Hospital and is part of a larger study aiming at the creation of a brief and inexpensive psycho-educational program that could become part of the standard specialized epilepsy care. To this end, we first
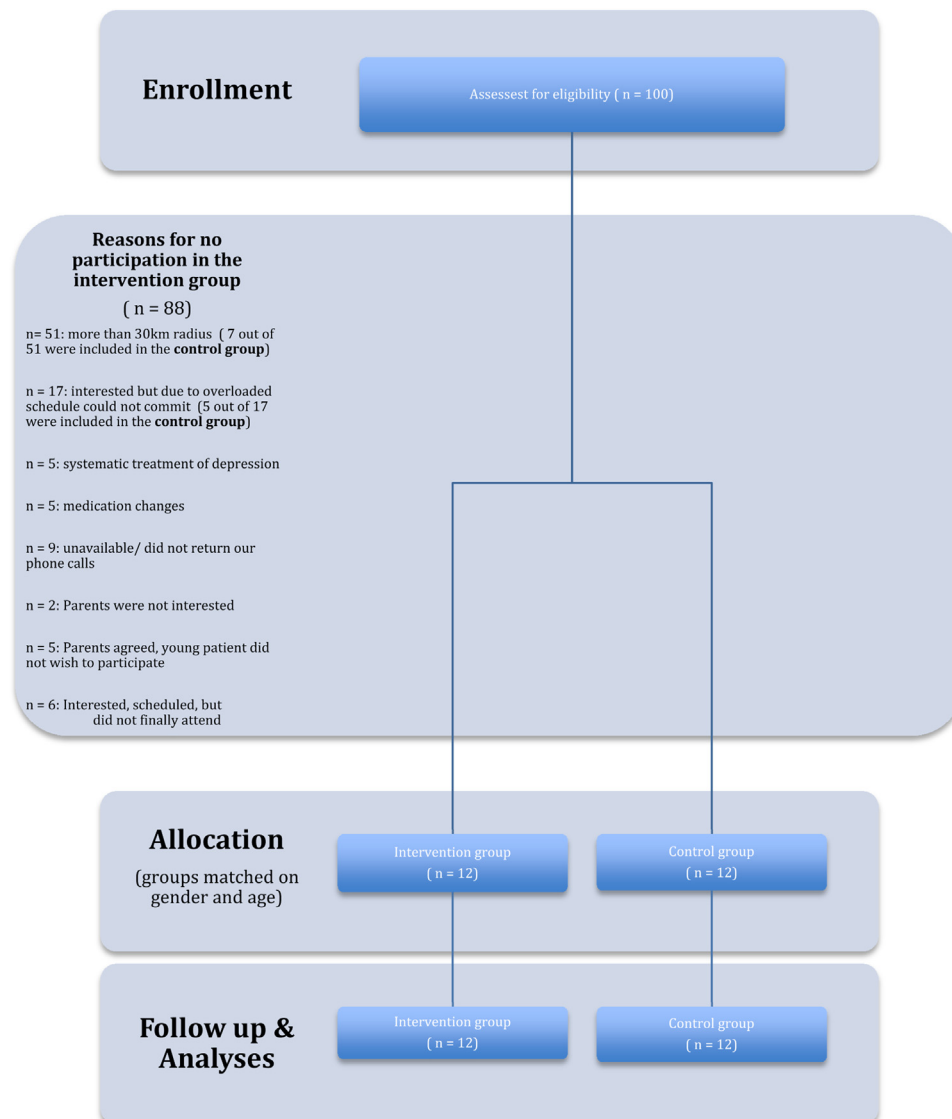


**Fig. 1.** Participant flow.

conducted studies that showed that illness cognitions explained important parts of the variance in psychological distress and quality of life as well as in fatigue and sleep problems in children and adolescents with epilepsy [2,3]. Based on these studies we developed the intervention, which is described below. This study is a pilot study with a small group of participants and controls that is primarily designed to (a) test the feasibility of the program and (b) its potential effectiveness. Based on the results of this study, adaptations can be made in view of a broader implementation of the program.

For the purpose of the present study intervention subjects were recruited according to the following inclusion criteria: 1) age: 10–18 years old, 2) at least one epileptic seizure during the preceding year, 3) normal IQ, 4) no other chronic illness, physical disability, or mental disorder, 5) no surgical procedures during the preceding year, 6) no medication change in the last 6 months, 7) no treatment for depression or anxiety (with medication and/or psychotherapy) and 8) living within a 30 km radius from the hospital.

Initially, 400 medical records of children and adolescents at the Epilepsy Clinic were consecutively examined and reviewed for their eligibility for the study. After examination of the medical records by a neurologist, children and adolescents who fulfilled the listed inclusion criteria were approached during their prescheduled visits and the first 100 who agreed to participate were included in a larger study that is described elsewhere [2,3].

The intervention group consisted of 12 out of the 100 participants. The flow of patients through the trial and reasons for non-participation in the intervention group are displayed in Fig. 1. After the formation of the intervention group, out of the remaining 88 subjects, a control group of 12 comparable children and adolescents was formed, matched by gender and age. For practical reasons and in order to avoid contact between members of the intervention and the control group, the groups were recruited in consecutive time periods.

### 2.2. Study variables

All data were obtained at baseline (before the start of the intervention for the intervention group) and at follow-up (3 months later) for both the intervention and the control group in the context of an interview. Except for disease characteristics, validated questionnaires were used to measure the outcomes. More specifically:

**Disease Characteristics** were derived from the medical records and included type of epilepsy, duration, age of onset, time of last seizure, total number of seizures and medication. The severity of epilepsy was evaluated on an ordinal scale with 6 categories. Starting from the least severe epilepsy, the categories were: 1) benign focal childhood epilepsy, 2) idiopathic generalized epilepsy, 3) epilepsy well controlled by medication but with unknown prognosis (unknown etiology of epilepsy), 4) symptomatic epilepsy with adequate response to medication (more than 6 months seizure free), 5) symptomatic epilepsy with moderate response to medication (less than 6 months seizure free), and 6) pharmaco-resistance (failure to respond to at least 3 appropriately selected anti-epileptics) [25]. With respect to this severity scale lower scores indicate lower epilepsy severity. This scale was constructed by us in order to combine syndrome related factors and several operational aspects of the patients' epilepsy. The scale was constructed in order to combine several disease factors into one severity score that could be correlated with the psycho-social outcomes [2,3].

**Illness Perceptions** were assessed using the validated **Brief Illness Perceptions Questionnaire (BIPQ)** [20]. Seven items measure cognitive illness representations (consequences, time-line, identity, personal and treatment control) and emotional

representations (concern and emotion). An additional item asks the patient to mention factors that according to his/her opinion caused the illness. A 10-point Likert scale is used to answer each item with lower scores indicating more beneficial perceptions (i.e. for timeline: 0 = my epilepsy will last for a very short time to 10 = it will last forever), except for coherence, personal and treatment control, where higher scores represent more beneficial perceptions.

**Psychological distress** was assessed with the validated **Revised Children's Anxiety and Depression Scale (RCADS)** [26]. This questionnaire consists of 47 items with 4 answer categories ("never", "sometimes", "often" and "always") and measures: 1) separation anxiety, 2) generalized anxiety, 3) panic, 4) social phobia, 5) obsessions/compulsions, 6) depression, 7) total anxiety, and 8) total anxiety and depression (psychological distress). In the present study, we used only the total psychological distress score with higher scores indicating more psychological distress.

**Sleep problems** were assessed with the validated **Athens Insomnia Scale (AIS)** [27,28]. This is an instrument designed to quantify sleep difficulty which consists of 8 items that refer to sleep induction, awakenings during the night, final awakening, total sleep duration, sleep quality, well-being, functioning capacity, and sleepiness during the day. Each item can be rated on a scale from 0 to 3 (with 0 corresponding to "no problem at all" and 3 "very serious problem"). A total score is calculated by adding up the scores for each item. Higher scores indicate more sleep problems. A cut-off of 6 for the total score can be used to define clinical levels of insomnia [28]. In the present study, the total score was used.

**Somatic complaints** were assessed with the **somatization scale of the validated Symptom Checklist 90-R** [29]. The scale consists of 12 items with 5 answer categories ("not true at all", "a little true", "somewhat true", "true", "very true") and measures headaches, faintness/dizziness, heart/chest/lower back pains, nausea/upset stomach, soreness of muscles, troubled breath, hot/cold spells, numbness/tingling in part of the body, lump in throat, feeling weak in parts of the body and heavy feeling in arms/legs. A total score was used with higher scores indicating more somatic complaints.

### 2.3. Duration and content of the intervention

Our initial plan was to implement the group intervention in 4 sessions, 2 h each, and to complement this with relevant homework material. We encountered, however, strong reluctance of some parents to comply with this schedule. Therefore, the intervention was limited to one group session that lasted 4 h without homework assignments, with the exception of the use of an epilepsy diary (see below). During this session information regarding the pathophysiology and treatment of epilepsy was provided and disease-related emotions and coping strategies were discussed from a self-management perspective. The young patients were especially encouraged to adopt a more self-regulatory attitude in managing their disease, especially regarding the treatment adherence, and to more actively participate in discussions about their illness with parents and health professionals.

### 2.4. Intervention method

For the educational part of the program a 10-min video was presented where all the necessary information regarding epilepsy (types of seizure, causes, treatment, first aid and also some social issues) was briefly discussed. This video has been produced by the Epilepsy Foundation of America in 2007 and is available for free view via https://www.youtube.com/watch?v=ZspAKmqydmM [30]. Greek subtitles have been added for our intervention. A

20-min discussion followed during which participants had the opportunity to clarify any misconceptions regarding epilepsy.

After completing the informative part of the intervention, we focused on illness perceptions and especially on personal control over the illness. The participants also had the opportunity to communicate their epilepsy related fears (e.g. "I am afraid that I might have a seizure at school and get humiliated again"), anger (e.g. "I don't understand why I should take the medication since I don't have seizures! I should stop taking the medication and if I get another seizure then start taking the medicine again!"), and discuss some of their considerations (e.g. "I haven't had any seizure for a long time and now I have a new boyfriend. Should I tell him that I have epilepsy or not?"). In addition, an epilepsy diary was introduced to the participants in order to help them to keep track of their medicine, seizures and the link with possible triggers.

In order to communicate with the young patients the Socratic process was used. The Socratic process provides a framework by which young patients identify, test and reappraise the important cognitive generalizations they use to interpret and understand their disease. Rutter & Friedberg identify a five-stage process that leads to the final step of logical deduction and systematic evaluation of key cognitions. The initial stage involves identifying important cognitions and in a next stage the feelings and behaviors associated with them. In a third stage the thought-feeling-behavior link is highlighted. The individuals are educated in this cognitive model so that they understand the relationship between what they think, how they feel and what they do. The fourth stage is concerned with reassessing and developing the collaborative relationship. The individuals' view about the 'think-feel-do' model is sought and in a final stage they move towards 'Socratic questioning' or in other words to challenge themselves their cognitions [31,32].

Simple relaxation techniques ("grounding" and "gradual body relaxation") were also presented, so as to provide an extra skill to our participants for self-managing their stress levels.

Lastly, storytelling was used in order to empower our young patients. The story's title was "The Eagle" (Permission to use the story was obtained from Mary Sue Siegel. The story is available via http://www.stories-that-heal.com/media/the_eagle-128kB.mp3) [33]. Although multiple topics for discussion may arise from this specific story, we chose to focus only on the importance of being open in receiving help, on acceptance of the self and on emotional resilience.

### 2.5. Statistical analysis

Descriptive analyses were performed for gender, age and epilepsy severity. Effects of the intervention on primary and secondary outcomes were examined using 2 (baseline, T1 vs. post-treatment, T2) x 2 (intervention vs. control) mixed model repeated measures analysis of covariance (ANCOVA), controlling for epilepsy severity. The intervention and control group were matched on gender and age. Illness perceptions, psychological distress, sleep problems and other somatic complaints were used as outcome measures.

## 3. Results

The 12 children and adolescents that constituted our intervention group (Age range = 10 – 17 years, Median age = 14, Mean age = 13.58, $SD$ = 1.92) consisted of 8 girls and 4 boys. The 12 patients that formed our control group were matched on gender and age and had therefore a comparable age and gender (Age range = 10 – 17 years, Median age = 14, Mean age = 13.62, SD = 1.94, girls = 8, boys = 4). No statistically significant difference between the intervention and control group was detected on severity ($M_{intervention}$ = 3.17 ($SD$ = 1.27) and $M_{control}$ = 2.67 ($SD$ = 1.30), $F_{(1,21)}$ = 0.35; $p$ = 0.56). The epilepsy severity characteristics of both groups are presented in Table 1.

Regarding illness perceptions, repeated-measures ANCOVAs revealed that over the three months of the study, significant main effects (group x time) were observed on coherence ($F_{(1,21)}$ = 6.12; $p$ = 0.02) with important changes in favour of the intervention group (T1: $M_{intervention}$ = 3.25 ($SD$ = 2.30) and $M_{control}$ = 5.83 ($SD$ = 2.85); T2: $M_{intervention}$ = 0.33 ($SD$ = 0.77) and $M_{control}$ = 4.83 ($SD$ = 2.40)). No statistically significant changes were noted on identity ($F_{(1,21)}$ = 1.85; $p$ = 0.18), timeline ($F_{(1,21)}$ = 0.19; $p$ = 0.66), consequences ($F_{(1,21)}$ = 1.28; $p$ = 0.27), personal control ($F_{(1,21)}$ = 3.31; $p$ = 0.08), treatment control ($F_{(1,21)}$ = 1.88; $p$ = 0.19), concern ($F_{(1,21)}$ = 1.61; $p$ = 0.22), nor on emotional representation ($F_{(1,21)}$ = 0.48; $p$ = 0.50) (Table 2).

As presented in Table 2, significant main effects (group x time) were also observed on psychological distress levels ($F_{(1,21)}$ = 10.08; $p$ = 0.005) and sleep problems ($F_{(1,21)}$ = 11.40; $p$ = 0.003), but not on somatic complaints ($F_{(1,21)}$ = 1.68; $p$ = 0.21). Improvements were noted in the intervention group, in distress (T1: $M_{intervention}$ = 77.08 ($SD$ = 13.11) and $M_{control}$ = 69 ($SD$ = 14.43); T2: $M_{intervention}$ = 62.75 ($SD$ = 6.82) and $M_{control}$ = 67.50 ($SD$ = 14.36)) and sleep problems (T1: $M_{intervention}$ = 6 ($SD$ = 3.04)) and $M_{control}$ = 3.67 ($SD$ = 3.31); T2: $M_{intervention}$ = 1.58 ($SD$ = 1.56) and $M_{control}$ = 3.67 ($SD$ = 2.67).

## 4. Discussion

The present study examined the feasibility and effectiveness of a brief self-regulation based intervention group program for children and adolescents with epilepsy.

Although our intervention consisted of only one four hour group session the analyses revealed favourable and statistically significant changes within and between the intervention and control group in some outcomes, more specifically in coherence (understanding of the disease), psychological distress and sleep problems. In addition, there was a tendency towards significance for personal control. We believe that our strict inclusion criteria resulted in a more homogenous group, which facilitated the

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**Table 1**
Epilepsy severity of treatment and control groups.

| Epilepsy severity | Treatment ($n$ = 12) | Control ($n$ = 12) |
|---|---|---|
| Benign focal childhood | 1 (8.3%) | 3 (25%) |
| Idiopathic generalized | 3 (25%) | 3 (25%) |
| Well controlled by medication-unknown prognosis | 3 (25%) | 5 (41.7) |
| Symptomatic with adequate response to medication (more than 6 months seizure free) | 3 (25%) | 1 (8.3%) |
| Symptomatic with moderate response to medication (less than 6 months seizure free) | 2 (16.7%) | 0 |

**Table 2**
Change in outcomes before and after the intervention.

| Outcome | Intervention | | Control | | Group effect | |
|---|---|---|---|---|---|---|
| | T1 Mean (SD) | T2 Mean (SD) | T1 Mean (SD) | T2 Mean (SD) | F | p |
| Identity | 1.92 (2.93) | 0.67 (1.23) | 2.92 (3.31) | 3.25 (2.95) | 1.85 | 0.18 |
| Timeline | 3.92 (3.28) | 3.17 (1.19) | 6.17 (3.07) | 5.92 (2.93) | 0.19 | 0.66 |
| Consequences | 1.67 (2.49) | 2.33 (2.77) | 7.00 (3.27) | 6.25 (3.07) | 1.28 | 0.27 |
| Coherence | 3.25 (2.30) | 0.33 (0.77) | 5.83 (2.85) | 4.83 (2.40) | 6.12 | 0.02 |
| Personal control | 2.08 (2.50) | 3.83 (1.46) | 3.08 (2.19) | 3.17 (1.99) | 3.31 | 0.08 |
| Treatment control | 1.33 (1.87) | 3.25 (3.44) | 2.42 (2.53) | 2.58 (1.67) | 1.88 | 0.19 |
| Concern | 4.67 (3.65) | 2.33 (1.67) | 6.83 (2.29) | 6.17 (2.12) | 1.61 | 0.22 |
| Emotional representation | 4.33 (3.31) | 2.33 (1.67) | 5.50 (3.47) | 4.67 (2.93) | 0.48 | 0.50 |
| Psychological Distress | 77.08 (13.11) | 62.75 (6.82) | 69 (14.43) | 67.50 (14.36) | 10.08 | 0.005 |
| Sleep problems | 6 (3.04) | 1.58 (1.56) | 3.67 (3.31) | 3.67 (2.67) | 11.40 | 0.003 |
| Somatic complaints | 15.25 (2.05) | 13.67 (2.18) | 14.33 (1.92) | 13.75 (1.76) | 1.68 | 0.21 |

delivery of the intervention and may have contributed to the intervention effects. Another reason for the effects may be the use of different intervention methods (video, cognitive behavior therapy, storytelling, and relaxation techniques). Other psycho-educational programs targeting children with epilepsy also used various intervention methods and it is believed that this is beneficial in terms of improvements [18]. Independent of this, especially Cognitive-Behavioural Therapy (CBT) has been proven beneficial not only at a psychological level, but also in terms of seizure frequency in patients with epilepsy [9,34].

### 4.1. Coherence

The evaluation of our intervention showed a positive effect on the understanding of the disease. Other programs for children and adolescents with epilepsy were also successful in increasing knowledge of epilepsy [14,35].

### 4.2. Psychological distress

Our intervention was successful in decreasing the psychological distress levels in our young patients. The Socratic five-stage approach may have been responsible for this effect. In addition, it should be noted that fundamental concerns of the participants such as fear of accidents and social embarrassment were also openly discussed. Other comparable programs also found a decrease in depression and anxiety after the intervention and suggested that addressing distress issues is also critical because of a strong association between distress and low levels of disease self-management [14,18,36–37].

### 4.3. Sleep problems

The analyses revealed that our intervention was also successful in decreasing sleep problems in our patients. To our knowledge, there is no other intervention study that targeted sleep problems in children and adolescents or even adults with epilepsy.

This study showed that our intervention was unsuccessful in affecting illness perceptions at a significant level other than coherence. There appeared to be, however, a tendency towards significance for personal control, suggesting that beneficial changes occurred in the intervention group in terms of personal responsibility in illness management. We believe that our intervention was not intensive enough to bring about changes in the other illness cognitions: understanding of the illness is easier to influence than illness beliefs. A more elaborate intervention is probably needed in this respect. In addition, illness perceptions (other than coherence and personal control) should probably be

explored and influenced at an individual level rather than at a group level [38]. As Corrigan et al state in their review of psychosocial interventions for children and adolescents with epilepsy, the 'high quality' CBT intervention studies included in their review provided individual treatment [9].

This study has several limitations. First of all the sample size of this pilot study may have reduced the ability to detect statistically significant group differences. In addition, patient recruitment for this intervention study proved to be difficult as our young patients were largely dependent on the availability and motivation of their parents to bring them back and forward to the hospital, but this is frequently observed in similar intervention studies [14]. Also, the fact that we decided to exclude children and adolescents with comorbidities and our strict inclusion criteria for participating in the intervention rendered recruitment difficult. As Jantzen et al. suggest, group homogeneity is, however, an important factor for satisfaction with the program [35]. Our inclusion criteria certainly increased the homogeneity within the groups, but may, at the same time, have reduced the generalizability of our findings. In addition, because of recruitment difficulty, the control group was not matched on epilepsy severity. Fortunately there appeared to be no difference in epilepsy severity between the intervention and the control group. Future studies should however use more differential severity measures and also screen for syndrome-specific psychological and psychiatric consequences, as they may account for cognitive and behavioural problems that interfere with psychological interventions or may require a specific intervention [39]. Furthermore, this intervention combined several intervention methods and the effect of these components cannot be separated. As other authors suggested, follow-up sessions and longer intervention duration might increase the effects of the intervention [10]. Furthermore, the 3-month follow-up after the completion of the program does not allow us to draw definite conclusions on the strength of the intervention effect over time. Although short follow-up periods have also been used in other studies [12,40], a longer follow-up period such as in the studies by Jantzen et al. and Martinovic et al is clearly preferable [35,41]. Lastly, the effect of the intervention could have been enhanced if we had also included the parent(s) of our young patients in the intervention. Previous studies have however demonstrated that similar interventions can be effective for children and adolescents with epilepsy without parental involvement [9,42].

This pilot intervention study is a first step in the development of an intervention program that could become part of standard specialized epilepsy care. In terms of feasibility we learned that an intervention with different sessions in time was inconvenient for several of the parents of the participants. Future studies should include a larger sample. We plan to do this by establishing a

multicenter collaboration as suggested by Corrigan et al. [9]. Furthermore, it can be questioned whether all patients are likely to profit to the same extent from this intervention. We suggest separating the informative/educational part and the stress management part (CBT + relaxation) of the intervention. While the informative/educational part can be offered to a larger group, the treating neurologist could, in collaboration with a mental health specialist, use brief validated self-report measures (e.g. for anxiety, depression, fatigue and sleep) in order to detect patients that would profit most from the stress management part. Finally, a separate educational part for parents and/or caregivers similar to the FLIP&FLAP or the FAMOSES programs may increase the effectiveness of patient directed interventions [35,43].

## 5. Conclusion

The results of this study show that a brief self-regulation-based intervention may have beneficial effects for children and adolescents suffering from epilepsy. The integration of affective, motivational and cognitive elements in the intervention might have influenced the positive changes observed. In addition, the intervention was well received by the participants. It remains to be seen whether the effects observed in our study will hold over time. It is important to influence mechanisms involved in the development and maintenance of distress and sleep problems in children and adolescents in order to support their autonomy and to contribute to the improvement of their overall quality of life.

## Conflicts of interest

## Funding

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