



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) × 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 × 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

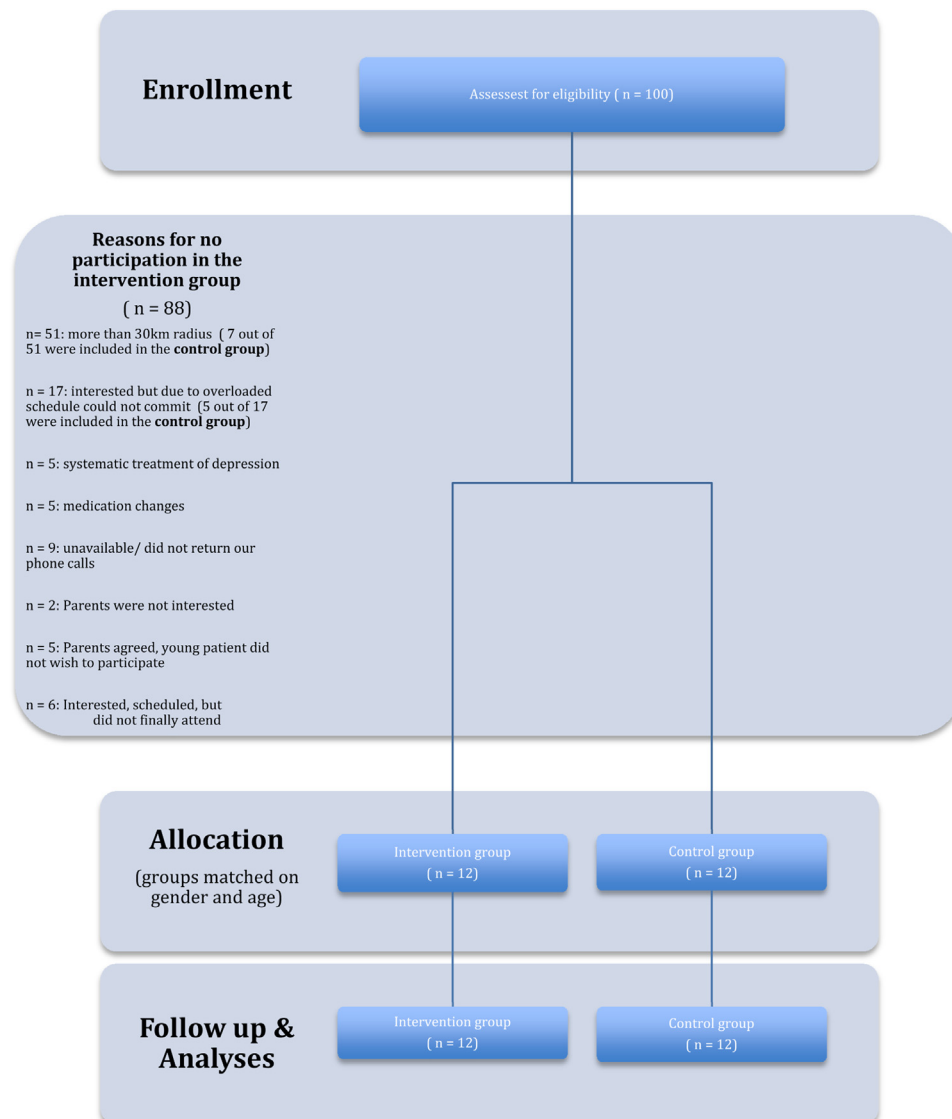


Fig. 1. Participant flow.

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