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The effect of a modular education program for children with epilepsy and their parents on disease management

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ABSTRACT

Objective: The objective of this study was to evaluate the efficacy of Modular Education Program for Children with Epilepsy and Their Parents on disease management. The program was prepared by researchers in an interdisciplinary team.

Method: Children with epilepsy and their parents were included in a randomized controlled study using a pre-posttest design. All participants of the modular education program ($n = 184$ (92 children and their 92 parents')) answered a lot of scales immediately before the program. The researcher presented the modular education program, which included eight modules (four for the children and four for the parents), to the children and parents in the intervention group using interactive teaching methods. And all participants of the modular education program answered all scales immediately after the program and one-month, three-month follow-ups. The control group not participating in the modular education program ($n = 100$ (50 children, 50 parents)) also answered all scales in all follow-ups. Scales used the study comprised epilepsy-specific outcome measures (e.g., knowledge, self-efficacy related to seizures, quality of life and anxiety). The statistical analyses of the study data were performed using SAS 9.3 software.

Results: Children in intervention group significantly improved in knowledge ($p < 0.001$), self-efficacy about seizures ($p < 0.001$), and quality of life ($p < 0.001$) compared with the control group. The parents in the intervention group also significantly improved in knowledge about epilepsy ($p < 0.001$) compared with the control group. However, anxiety of the parents in the intervention group significantly increased ($p < 0.001$).

Conclusion: The efficacy of the Modular Education Program for Children with Epilepsy and Their Parents on disease management was confirmed. The results indicate that using interactive teaching methods help children with epilepsy and their parents in improving knowledge, self-efficacy about seizures and quality of life. All health professionals who work with children with epilepsy and their parents should provide these modular education programs regularly.

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1. Introduction

Epilepsy is a chronic disease that is characterized by two or more unprovoked seizures [1] and affects about 50 million people around the world [2]. It is one of the most common diseases among children and adults [3]. Serdaroğlu et al. [4] reported that the prevalence of epilepsy among Turkish children under 16 years of age was 0.8%. Although some of these seizures can be successfully managed with medication or other types of treatment, epilepsy has a negative effect on professional, educational, and social life and can cause psychological problems [5]. The most common problems related to epilepsy are loss of control and

autonomy, anxiety caused by seizures, depression, social stigmatization, parental overprotectiveness, excessive dependence on parents, failure to adapt to the disease, and failure to cope with the disease [6–9]. This has a negative effect on the quality of life of children with epilepsy and their parents [5,9,10,11].

To examine the causes of the problems related to epilepsy, various analyses have been performed. The results of these analyses have indicated that families and children with insufficient knowledge about the disease have more problems [6–8,10,12,13]. The relevant literature shows that patients with epilepsy wish to be informed about psychosocial issues related to epilepsy (seizures and how to control them, prevention of injuries, social issues, work environment and opportunities, prognosis, and lifestyle) [10,14,15].

Education is one of the most important factors in the attainment of desired health behaviors [16]. The objectives of educational and consultancy programs are to increase the knowledge, treatment adaptation,

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and quality of life of the entire family and to reduce the frequency of seizures and the costs of care and treatment.

The management of epilepsy requires an interdisciplinary team approach. In this team, the pediatric nurse, who works most with the child and family, has important training and consultancy responsibilities. Nurses can help children and parents to manage the disease effectively by providing training programs and enabling them to access accurate and sufficient knowledge about the disease. Epilepsy nurses do routine epilepsy care and are its center. The current clinical guidelines for epilepsy emphasize that nursing models should include child-centered training [17]. This may make it easier for children to improve their self-efficacy regarding seizures and to increase their quality of life [11,18]. Previous studies have found that the nursing care provided to children with epilepsy and to their parents facilitates their coping with the disease. It also increases the quality of life of both children and parents [19–22].

Modular education programs prepared in Germany and Switzerland for children with epilepsy and their parents have been successfully implemented on a regular basis [21,23–25]. In Turkey, however, there are no studies that focus on epilepsy management and use interactive teaching methods with children and parents in a modular education program. The objective of this study was to evaluate the efficacy of the Modular Education Program for Children with Epilepsy and Their Parents on disease management.

2. Methods

2.1. Participants and study design

This randomized controlled study was conducted between January and June 2014 with children, ranging in age from 7 to 18 years, who have epilepsy but no mental deficiencies and visited the pediatric neurology polyclinic of a university hospital in Antalya, Turkey, and with their parents.

2.1.1. Inclusion criteria

The criteria for the children were being between the ages of 7 and 18 years, having had epilepsy for at least six months, having no mental deficiencies, being literate, and agreeing to participate in the study. Psychometric testing was performed to learn the intelligence levels of children with epilepsy in the clinic. These results were recorded in the children's files. As a result, children without mental deficiencies were included in the study. The criteria for the parents were being literate and agreeing to participate in the study. A pilot test was conducted with ten children and their parents who were not included in the main study.

The records of the previous year were examined in order to reach the number of appropriate cases in the study. In the first half of 2013 in the Akdeniz University Hospital Pediatric Neurology Polyclinic, 180 of the 300 children who applied with the diagnosis of epilepsy are in

Table 1
Modular education program for children with epilepsy.

Modules	Content	Activities	Methods	Materials
Module 1 Knowledge About Epilepsy	– What is Epilepsy? – Symptoms of Epilepsy	– Question and answer – Discussion – Brainstorming – Role playing – Demonstration and implementation of certain activities	– Slides – Videos	– Brochure – 1 flipchart – Guide to Living with Epilepsy
Break time				
Module 1 continued Knowledge About Epilepsy	– Diagnosis of Epilepsy – Treatment of Epilepsy – Complementary Alternative Approach in Epilepsy	– Discussion – Brainstorming – Role playing – Demonstration and implementation of certain activities – Playing game – Abstract of module	– Slides – Videos	– Brochure – 1 flipchart – Guide to Living with Epilepsy
Break time				
Module 2 Epilepsy and I	– Living with Epilepsy – What do I think about my illness? – What do people think about my illness?	– Question and answer – Discussion – Brainstorming	– Slides – Videos	– Brochure – 1 flipchart – Guide to Living with Epilepsy
Break time				
Module 2 continued Epilepsy and I	– What should I look for in my daily life? – What do I need to be aware of nutrition? – What do I need to be careful while watching TV, playing computer, using mobile phone and sleeping?	– Question and answer – Discussion – Brainstorming – Abstract of module	– Slides – Videos	– Brochure – 1 flipchart – Guide to Living with Epilepsy
Break time				
Module 3 Seizure Management	– How can I manage seizure? – What should I do to prevent seizure development? (sleeping etc.)	– Discussion – Brainstorming – Symptoms (sweating, tachycardia ex)	– Slides – Videos	– Brochure – 1 flipchart – Guide to Living with Epilepsy
Break time				
Module 3 continued Seizure Management	– What should I pay attention to when using medicine?	– Discussion, – Abstract of module	– Slides – Videos	– Brochure – 1 flipchart – Guide to Living with Epilepsy – Antiepileptic drugs
Break time				
Module 4 Epilepsy and Social Life	– Does my disease affect my social life? – Is there anything that I have to stop doing because of my illness? (sport etc.)	– Discussion – Question and answer – Brainstorming	– Slides – Videos	– Brochure – 1 flipchart – Guide to Living with Epilepsy
Break time				
Module 4 continued Epilepsy and Social Life	– Epilepsy and School – Epilepsy and Sport – Marriage and having a baby – Computer, mobile phone – Sleeping	– Discussion – Question and answer – Brainstorming – Abstract of module	– Slides – Videos	– Brochure – 1 flipchart – Guide to Living with Epilepsy

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