

Planlı Eğitimin Epilepsili Çocuklarda Yaşam ve Uyku Kalitesine Etkisi

The Effect of Planned Education on Quality of Life and Sleep of Children with Epilepsy

Selin DEMİRBAĞ¹ A,B,C,D,E,F, ^{ORCID}, Dilek ERGİN¹ A,B,F,G, ^{ORCID}, Muzaffer POLAT² A,B,G, ^{ORCID}

¹Manisa Celal Bayar University, Faculty of Health Sciences, Department of Child Health and Disease Nursing, Manisa, Turkey

²Manisa Celal Bayar University, Faculty of Medicine, Department of Pediatric Neurology, Manisa, Turkey

ÖZ

Amaç: Bu araştırmanın amacı, epilepsili çocuklara verilen planlı eğitimin yaşam ve uyku kalitesine etkisini değerlendirmektir.

Yöntem: Çalışma, 2 Haziran-2 Kasım 2017 tarihleri arasında Türkiye'de Manisa Celal Bayar Hastanesi'nde 37'si deneysel, 37'si kontrol olmak üzere toplam 74 epileptik çocuk ile yarı deneysel bir çalışma olarak gerçekleştirildi. Deneysel gruba planlı eğitim ve yazılı eğitim materyali verildi. Birinci anket formu (ön test) uygulamasından bir ay sonra her iki gruba da ikinci anket formu (son test) uygulandı. Çalışma sonunda kontrol grubuna eğitim ve yazılı eğitim materyali (eğitim kitapçığı) verildi. Araştırma verilerinin toplanmasında Çocuk Tanıtım Formu, Genel Çocuk Yaşam Kalitesi Ölçeği, KINDL Epilepsili Çocuklar İçin Yaşam Kalitesi Modülü, Pittsburgh Uyku Kalitesi İndeksi kullanıldı.

Bulgular: Deneysel grubunun Genel Çocuk Yaşam Kalitesi Ölçeği son test puan ortalamalarının ön test puan ortalamalarından yüksek olduğu ve aradaki farkın anlamlı olduğu bulundu ($p<0.05$). Deneysel grubunun Pittsburgh Uyku Kalitesi İndeksi son test ortalaması ön test ortalaması puanlarından düşük olduğu, çocukların uyku kalitelerinin arttığı ve aradaki farkın anlamlı olduğu bulundu ($p<0.05$).

Sonuç: Pediatri hemşireleri, çocuğun hastalıkla ilgili bilgi düzeyi, algılama biçimi ve tedaviye uyumunu değerlendirerek çocuğa yönelik eğitimin planlanması ve sürekliliğinin sağlanması yoluyla çocuğun yaşam ve uyku kalitesini artırmalıdır.

Anahtar Kelimeler: Epilepsi, Yaşam kalitesi, Uyku kalitesi, Çocuk.

ABSTRACT

Objective: The purpose of this research is to evaluate the effect of planned education on life and sleep quality given to children with epilepsy.

Method: The study was conducted as a quasi-experimental study with a total of 74 epileptic children, 37 of whom were intervention and 37 of whom were controls between 2nd of June-2nd of November 2017 at Manisa Celal Bayar University Hospital, Turkey. Planned education and written education material were provided to the intervention group. One month after the first questionnaire (pretest) application, the second questionnaire form (posttest) was applied to both groups. At the end of the study, education, and written education material (education booklet) were provided to the control group. Child Introduction Form, The Generic Children's Life Quality Measure, KINDL Epilepsy Related Quality of Life Module for Children, Pittsburgh Sleep Quality Index were used to collect research data.

Results: It was found that the intervention group's Generic Children's Life Quality Measure posttest average scores were higher than their pretest average scores and the difference between them was significant ($p<0.05$). It was found that the Pittsburgh Sleep Quality Index posttest average scores of the intervention group were lower than the pretest average scores, the sleep quality of children increased and the difference between them was significant ($p<0.05$).

Conclusion: Pediatric nurses should increase life and sleep quality of child by planning and ensuring the continuity of education for child evaluating child's level of knowledge about the disease, his/her perception form, and compliance with treatment.

Key words: Epilepsy, Quality of life, Sleep quality, Child.

Corresponding Author: Selin DEMİRBAĞ

Manisa Celal Bayar University, Faculty of Health Sciences, Department of Child Health and Disease Nursing, Manisa, Turkey
selin.demirbag.cbu@gmail.com

Geliş Tarihi: 13.04.2023 – Kabul Tarihi: 15.09.2023

* The Abstract was presented as an oral presentation in the 4th PNAE Congress on Paediatric Nursing. Athens, Greece on 1-2 June 2018. The manuscript was part of a research of Master of Degree.

Yazar Katkıları: A) Fikir/Kavram, B) Tasarım, C) Veri Toplama ve/veya İşleme, D) Analiz ve/veya Yorum, E) Literatür Taraması, F) Makale Yazımı, G) Eleştirel İnceleme

1. INTRODUCTION

In childhood, one of the most common neurological disorders is epilepsy. Epilepsy is a condition that affects not only physical functionality but also cognitive, behavioral, and emotional functionality (1). Epilepsy, a common neurological disorder affecting children, is characterized by recurrent and unprovoked seizures (2).

Health-related life quality is a widely accepted outcome measure of health and illness and is used to assess the impact of a disease and its treatment on functioning (3). Epilepsy significantly decreases the health-related life quality in children by affecting emotional, behavioral, social, school and family related factors (4).

One of the most common co-morbidities in epilepsy is sleep problems (5). Sleep disorders are observed to aggravate epilepsy by increasing the frequency of seizures and sometimes cause treatment-resistant epilepsy and create a vicious circle between epileptic phenomena and sleep disorders (6). Sleep disorders also cause cognitive and behavioral problems (7). This situation also has an important effect on the deterioration of physical health. Therefore, it can be expected that the health-related life quality of children with sleep problems deteriorates.

The study was carried out to investigate the effect of planned educational intervention on life and sleep quality in children with epilepsy.

2. METHOD

Design and Setting

The study was conducted as a quasi-experimental study. The study group consists of 74 children in the 8-16 age groups who applied to Manisa Celal Bayar University Hospital Pediatric Neurology Outpatient Clinic between 2nd of June-2nd of November 2017, followed up with a diagnosis of epilepsy and volunteered to participate in the study. As a result of the lot made by the researcher, children with epilepsy with double protocol number were determined as experiment (n=37), and children with single protocol number were determined as control (n=37) groups. Since the study aims to evaluate the children's the life quality as a result of the intervention, it is of vital importance for the data of study results that the children included are able to understand the provided education and the education booklet. Therefore, school-age and adolescent children were included in the study. Post hoc power analysis was performed for the sample size in the G-Power (3.1.9.6) program by using the posttest scores and the determination of the power of the research. In this analysis, the power of the study was found to be 96%, based on 95% confidence interval and p=0.05 significance level, using t test analysis data in independent groups.

Data Collection

Face-to-face interview technique was used to collect data. One month after the first questionnaire (pretest) application, the second questionnaire form (posttest) was applied to both groups. The average application time of the questionnaire forms is 20 minutes (Figure 1).

After the pretest application, the intervention group was given a planned and 20-minute education on "Life and Sleep Quality in Children with Epilepsy", which was prepared by

including the literature information and 5 expert opinions obtained from two faculty members from the Department of Pediatric Health and Diseases Nursing, two faculty members from the Department of Pediatric Neurology, and a faculty member from the Department of Child and Adolescent Mental Health. The education was conducted by the researcher in the form of a power-point presentation via the computer at different times for each child. Afterwards, an education booklet containing the topics of the planned education made by the researcher was handed out. Only the pretest and the posttest were applied to the control group. After the posttest was applied to the control group, education was provided, and education booklet was handed out.

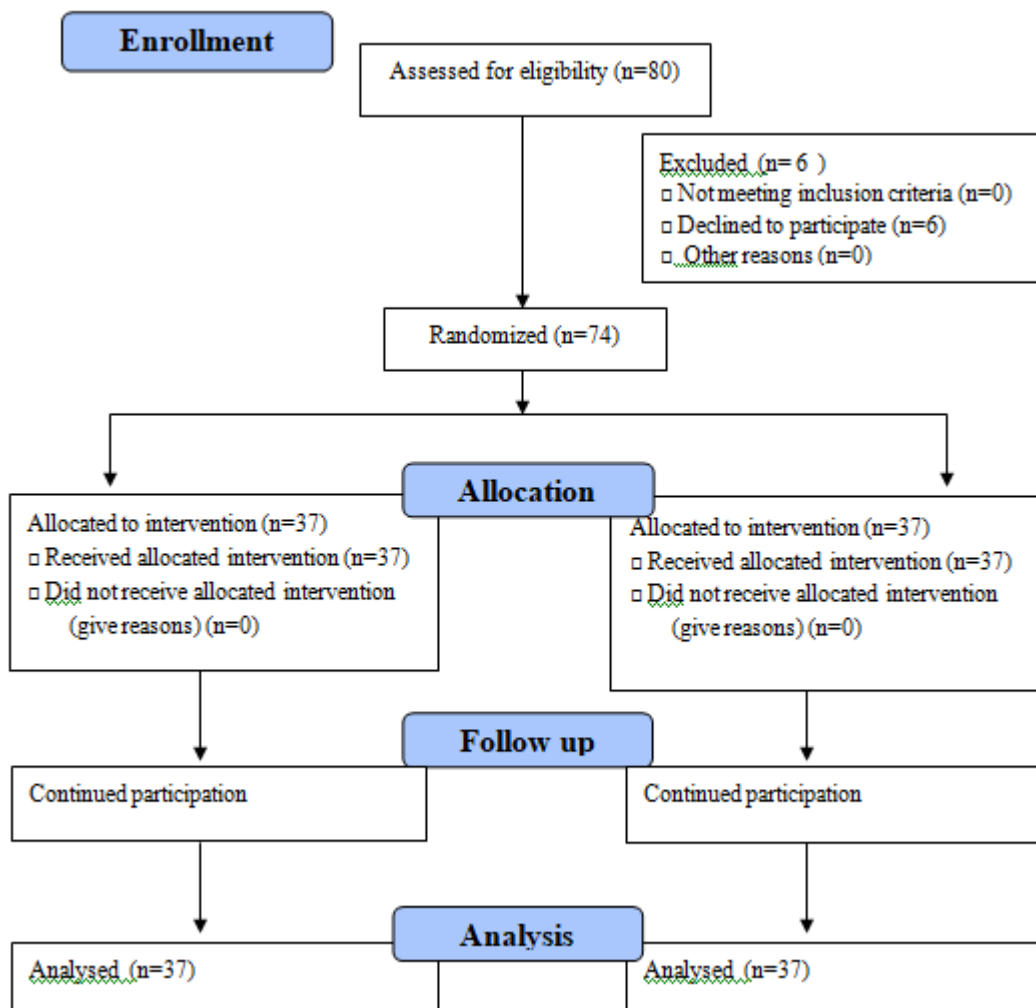


Figure 1: Participant Flow and Allocation

Instruments

The Child Identification Form contains data on the age, gender, seizure type, hospitalization status, medications used, sleep problems, epilepsy diagnosis age and daily sleep time of the children with epilepsy.

The Generic Quality of Life Scale for Children (KINDL)

The Generic Quality of Life Scale for Children (KINDL) was developed by Ravens-Sieberer and Bullinger (1998) and has been adapted to Turkish by Eser et al. (2008) based on self-report, there are versions of Kid-KINDL for 8–12-year-olds and Kiddo-KINDL for 13–16-year-old adolescents. The scale is of a five-point Likert type, and it has 30 items. The scale consists of four items in each of the sub-dimensions of friends, school, self-esteem, family, physical well-being, mental well-being, and the chronic domain dimension consists of six items. Negatively oriented items (1, 3, 4, 6, 7, 8, 15, 16, 20 and 24th questions) were scored by reversing according to the writing style of the question. The score is calculated by counting the points given to the items for each dimension, scaling between 0-100 and converting them. The total Cronbach Alpha internal consistency value of the scale is 0.78. High score indicates good health-quality of life (8).

The KINDL Epilepsy Quality of Life Module for Children

The KINDL Epilepsy Quality of Life Module for Children is an additional disease module of the KINDL Generic Quality of Life Scale for Children. The scale consists of 31 items (index criteria) and additionally five treatment satisfaction questions. The score is calculated by scaling and transforming the module between 0-100. For the KINDL Generic Scale and the Epilepsy Module, Baseline (0.0–0.0%) and Peak effects (2.5–10.0%) were found to be within acceptable limits. The internal consistency of the module size was 0.91, and the internal consistency of treatment satisfaction was 0.51 (9).

Pittsburgh Sleep Quality Index

Pittsburgh Sleep Quality Index (PSQI) was developed by Buysse et al. (1989). It adapted to Turkish by Agargun et al. (1996). PSQI is a 19-item self-report scale that evaluates sleep quality and disorder over the past month. The scale consists of 24 questions and each component with seven components is evaluated on a score of 0-3. The total score is between 0-21. A total score greater than five indicates "poor sleep quality". The Cronbach alpha coefficient is 0.80 (10).

The Epilepsy Education Module

The Epilepsy Education Module was prepared by the researchers in the form of an epilepsy education module and an education booklet. This booklet was distributed to provide revision and to create a resource that children can access whenever they want, outside the education session. The session was carried out individually in the form of face-to-face presentations, questions, and answers, and interactively. At the end of the preliminary interviews carried out with 8 children with epilepsy by the researcher, a lack of information was detected. Based on the Epilepsy Guide of the Epilepsy Working Group of the Turkish Neurological Association (2015), an education module was prepared that includes children's lack of knowledge (11). After it was created, amendments were made based on 5 expert opinions obtained. The education includes information on the definition, classification, etiology and methods for coping with epilepsy. The education booklet containing this information was provided to the children after the education. The working group is between the ages of 8-16. It

covers the concrete operational stage (7-11 years old) and the abstract operational stage (11+years old) according to Piaget. For this reason, the content of the education for each age group of the children was prepared with the consideration of the developmental characteristics of the children. For example, picture cards, brochures, films are reported as useful in education in this age group. During the presentation, care was taken to concretize and explain the content of the education. Visual examples were included in the education, as well.

Data Analysis

SPSS (Statistical Package for Social Sciences) 15.0 program was used for data analysis. Kolmogorov-Smirnov test was used to evaluate the normal distribution. Descriptive statistical analysis (number-percentage distribution) was performed. For the continuous data comparison in both groups, T Test in Dependent Groups, T Test in Independent Groups, Wilcoxon Signed Ranks Test, Mann Whitney U Test for data that did not comply with normal distribution, and Chi-square test for categorical variables were used. The results of the research data were accepted as 95.0% confidence interval and $p < 0.05$ significance level.

3. RESULTS

Descriptive characteristics of children with epilepsy are indicated in Table 1. The average age of the intervention and control groups are 12.08 ± 3.03 , 11.10 ± 2.69 years, respectively. It was determined that all variables evaluated were similarly distributed, except for the age of diagnosis of epilepsy in both groups, and the age of diagnosis of the intervention group was significantly higher than the control group, statistically.

Table 1. Sociodemographic Characteristics and Disease-Specific Features (n=74).

VARIABLE	Intervention Group		Control Group		p
	n	%	n	%	
Age					^a 0.475
8-12 age	21	56.8	24	64.9	
13-16 age	16	43.2	13	35.1	
Gender					^a 0.816
Male	19	51.4	18	48.6	
Female	18	48.6	19	51.4	
Epilepsy type					^a 0.760
Generalized	30	81.1	31	83.8	
Focal/partial	7	18.9	6	16.2	
Treatment type					^a 1.000
Monotherapy	29	78.4	29	78.4	
Multitherapy	8	21.6	8	21.6	
Hospitalization					^a 0.816
Yes	18	48.6	19	51.4	
No	19	51.4	18	48.6	
Trouble with sleep					^a 0.815
Yes	17	45.9	16	43.2	
No	20	54.1	21	56.8	
	Mean±SD		Mean±SD		
Age	12.08±3.03		11.10±2.69		^c 0.169
Age of onset of the disease	8.89±3.31		6.73±3.81		^b 0.011
Daily sleep time	8.83±1.09		8.81±1.41		^c 0.880

^aKi-kare Test, ^bIndependent Samples T Test, ^cMann Whitney U Test, SD:Standard deviation

The results of the KINDL and KINDL Epilepsy Quality of Life Module for Children are indicated in Table 2. It was found that there was no statistically significant difference in the pretest results of the KINDL for Children in both groups in all areas of the life quality and in the total life quality average scores ($p>0.05$). As a result of the KINDL Children posttest application, the total average scores of life quality and self-esteem of the intervention group were found to be significantly higher than the control group, statistically. It was determined that the average scores of total life quality, physical and self-esteem increased significantly between the pretest and posttest results in the intervention group. In the control group, between the pretest and posttest results, it was determined that a statistically significant decrease was observed in the total quality of life, physical, mental and school life quality scores ($p<0.05$).

Table 2. Distribution Properties of the KINDL-TR Epilepsy Module and KINDL Generic Scale

		Pre test	Post test	
		Mean±SD	Mean±SD	p
KINDL Generic Scale	Physical			
	Invention group	67.22±18.00	72.46±20.48	^c 0.009
	Control group	69.08±18.09	63.51±21.37	^a 0.006
	p	^b 0.624	^d 0.070	
	Mental			
	Invention group	72.29±18.54	71.11±19.28	^a p:0.526
	Control group	69.08±15.16	64.86±15.33	^c 0.000
	p	^b 0.239	^d 0.096	
	Self-esteem			
	Invention group	69.42±13.95	75.16±13.37	^c 0.000
	Control group	62.16±16.26	60.13±15.33	^a 0.163
	p	^b 0.082	^d 0.000	
	Family relations			
	Invention group	66.38±16.68	66.72±16.00	^c 0.803
	Control group	69.25±13.61	67.73±14.16	^a 0.163
	p	^b 0.420	^d 0.991	
	Friend relations			
	Invention group	71.62±16.44	72.46±17.70	^c 0.581
	Control group	71.62±15.56	70.43±17.28	^a 0.294
	p	^b 0.865	^d 0.620	
School				
Invention group	60.13±17.45	59.79±17.71	^c 0.768	
Control group	54.05±21.05	50.67±21.43	^c 0.005	
p	^b 0.181	^d 0.050		
Chronic illness module				
Invention group	62.27±15.49	62.83±17.07	^c 0.690	
Control group	57.54±18.65	55.51±19.09	^c 0.074	
p	^b 0.240	^d 0.087		
Total score				
Invention group	67.84±9.29	69.62±11.01	^c 0.029	
Control group	65.87±9.36	62.89±11.03	^c 0.001	
p	^b 0.367	^d 0.011		
KINDL Epilepsy Module	Total score			
	Invention group	74.76±11.53	74.56±12.26	^a 0.820
	Control group	73.01±9.68	71.55±10.63	^c 0.035
	p	^b 0.320	^d 0.097	
	Treatment			
Invention group	78.10±14.49	79.18±12.38	^c 0.544	
Control group	74.18±15.65	67.83±13.56	^c 0.010	
p	^b 0.268	^d 0.000		

^aWilcoxon Signed Ranks Test, ^bMannWhitney U Test, ^cStudent's T Test, ^dIndependent Samples T Test, SD:Standard deviation

It was found that there was no statistically significant difference between the pretest and posttest total scores of the intervention group in the KINDL Epilepsy Quality of Life Module for Children ($p>0.05$). It was found that the posttest scale total score of the control group decreased and there was a statistically significant difference in the KINDL Epilepsy Quality of Life Module for Children ($p<0.05$). It was found that there was no statistically significant difference between the pretest and posttest treatment satisfaction scores of the intervention group ($p>0.05$). It was found that the posttest treatment satisfaction score of the control group decreased and there was a statistically significant difference ($p<0.05$).

Table 3 shows the results of the PSQI. In the posttest of the intervention group, it was found that the scale total score and sleep disturbance score decreased, this was statistically significant, and their sleep quality increased ($p<0.001$). There was no significant change in the sleep quality of the control group ($p>0.05$).

Table 3. Distribution Properties of the Pittsburgh Sleep Quality Index (n=74).

Pittsburgh Quality Index	Sleep	Pre Test	Post Test	p
		Mean±SD	Mean±SD	
Sleep quality				
Invention group		1.62± 0.63	0.83±0.72	^a 0.000
Control group		1.16± 0.92	1.00±0.81	^a 0.333
p		^b 0.024*	^b 0.420	
Sleep onset latency				
Invention group		2.94± 0.22	3.00±0.00	^a 0.157
Control group		2.97±0.16	2.91±0.27	^a 0.317
p		^b 0.558	^b 0.079	
Sleep duration				
Invention group		0.00±0.00	0.00±0.00	^a 1.000
Control group		0.00±0.00	0.00±0.00	^a 1.000
p		^b 1.000	^b 1.000	
Sleep efficiency				
Invention group		0.02±0.16	0.00±0.00	^a 0.317
Control group		0.00±0.00	0.00±0.00	^a 1.000
p		^b 0.317	^b 1.000	
Sleep disturbance				
Invention group		1.00±0.33	0.81±0.46	^a 0.020
Control group		0.97±0.49	0.97±0.55	^a 1.000
p		^b 0.775	^b 0.191	
Hypnotic drugs				
Invention group		0.00±0.00	0.00±0.00	^a 1.000
Control group		0.00±0.00	0.00±0.00	^a 1.000
p		^b 1.000	^b 1.000	
Daytime dysfunction				
Invention group		0.00±0.00	0.00±0.00	^a 1.000
Control group		0.00±0.00	0.00±0.00	^a 1.000
p		^b 1.000	^b 1.000	
Global score				
Invention group		5.52± 0.79	4.64±1.05	^a 0.000
Control group		5.13 ±1.29	4.81±1.22	^c 0.135
p		^b 0.048	^b 0.845	

^aWilcoxon Signed Ranks Test, ^bMannWhitney U Test, ^cStudent's T Test, SD:Standard deviation

4. DISCUSSION

In our study, it is observed that the Generic Quality of Life Scale for Children total score average of the children in the intervention group was not high in the pretest, but the posttest scores increased. In studies conducted with children with epilepsy, it was found that the life quality of children significantly increased as a result of the education provided for the children and their families (12,13). Our study results, which are similar to other research results, show that the planned education given to children with epilepsy increases the Generic Quality of Life for Children. With the planned education, it is important for the children with epilepsy to learn to live with epilepsy, to increase their knowledge about their diseases and to give them responsibility, for the child to gain independence and adapt to treatment. It was concluded that the planned education had an effect on the life quality of children with epilepsy by resulting in a positive change in the quality of their lives.

According to our research results, it was found that there was no change in KINDL Epilepsy Quality of Life levels and treatment satisfaction levels in the intervention group after the education, while there was a significant decrease in KINDL Epilepsy Quality of Life levels and treatment satisfaction levels in the control group. It is considered that as a result of providing the children with epilepsy with the planned education including fundamental information about epilepsy, the decrease in the score of KINDL Epilepsy Quality of Life and treatment satisfaction was prevented, thus the intervention group's KINDL Epilepsy Quality of Life and treatment satisfaction score remained the same. It is seen in the studies that the disease-specific life quality scales rather than the scales measuring the general life quality of children provide better and more accurate results (14,15,16). Reasons such as hospitalization, foreign environment, excess of caregivers, uncertainty cause the child to experience fear and anxiety. This situation is known to reduce the child's life and sleep quality (17,18,19). It is considered that the expected decline in life quality and sleep remain the same thanks to the education provided.

It is observed that the sleep quality of the children in the intervention group was poor, but it improved in the posttest evaluation. Keskin et al. found in a 2011 study that patients with epilepsy had poor sleep quality (20). Gutter et al. found in their 2013 study that children with epilepsy who have sleep disorders have worse sleep quality (21). Ekinçi et al. found in a study conducted in 2016 that the life quality of children with epilepsy with lower sleep quality was significantly less (5). The results of the study, which are similar to the results of other studies, show that the sleep disturbance of children with epilepsy in the intervention group decreased, sleep quality increased, and the control group remained the same (22). Education is essential in detecting the mistakes made by children with epilepsy and correcting these mistakes. It was concluded that the planned education provided in our study made positive results in the sleep disturbance of the children changed positively and increased their sleep quality.

Limitations of Research

Conducting the study in a single center, the results of this study can only be generalized to the individuals in the research group.

5. CONCLUSION

With the education provided to children with epilepsy, an increase in the children's physical, self-esteem and total life quality. In the control group, a deterioration was found in physical, mental, school, and total life quality scores. KINDL Epilepsy Quality of Life Module and treatment satisfaction levels decreased significantly in the control group. Sleep quality also increased in the intervention group. For this reason, pediatric nurses should create and implement educational programs for the child in order to develop the life and sleep quality of the child with epilepsy.

Acknowledgements

The authors would like to thank the children who took part in this study.

Ethical Consideration of the Study

For the research, an approval dated 10/05/2017 and numbered 20.478.486 was obtained from the Scientific Research and Publication Ethics Board of Manisa Celal Bayar University, and a written institutional permission was obtained from the institution where the research was carried out. Verbal and written consent was obtained from the children who agreed to participate in the study and their parents.

Conflict of interest statement

The authors declare no conflict of interest.

Funding

The authors did not receive support from any organization for the submitted work.

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