İSTANBUL UNIVERSITY PRESS

Çocuk Dergisi–Journal of Child,
JCHILD 2025, 25 (2): 97–104

https://doi.org/10.26650/jchild.2025.1722249

Submitted: 18.06.2025
Accepted: 03.07.2025

Çocuk Dergisi
Journal of Child

Research Article

Open Access

What are The Barriers to Initiating or Sustaining The Ketogenic Diet in Pediatric Patients; Single Centre Experience

Gulten Ozturk [1], Hakkı Akbeyaz [1], Ebru Acar [2], Olcay Ünver [1] & Dilşad Türkdoğan [1]

[1] Marmara University Pendik Education and Research Hospital, Pediatric Neurology,Istanbul, Türkiye
[2] Marmara University Pendik Education and Research Hospital, Nutrition and Dietetics,Istanbul, Türkiye

Abstract

Objective: The ketogenic diet (KD) is an effective treatment for drug-resistant epilepsy in children. Despite its proven efficacy, a considerable number of eligible patients do not initiate or discontinue therapy prematurely. This study aimed to investigate the barriers to KD initiation and continuation following structured education provided by a specialized ketogenic care team.

Materials and Methods: This retrospective study included pediatric patients referred to the Ketogenic Diet Clinic at Marmara University between 2014 and 2024 who either did not initiate the KD or discontinued it within the first three months. Out of 250 patients educated about the KD, 140 met the inclusion criteria and were contacted by phone. Seventy-two patients agreed to participate. Data were collected using a structured questionnaire and analyzed using descriptive statistics, chi-square and Mann-Whitney U tests, and logistic regression modeling to identify potential predictive factors.

Results: This retrospective study included pediatric patients referred to the Ketogenic Diet Clinic at Marmara University between 2014 and 2024 who either did not initiate the KD or discontinued it within the first three months. Out of 250 patients educated about the KD, 140 met the inclusion criteria and were contacted by phone. Seventy-two patients agreed to participate. Data were collected using a structured questionnaire and analyzed using descriptive statistics, chi-square and Mann-Whitney U tests, and logistic regression modeling to identify potential predictive factors.

Conclusion: Barriers to KD implementation were largely related to caregiver concerns, perceived dietary complexity, and doubts about effectiveness. These findings highlight the need for enhanced education, individualized support, and structured follow-up strategies to improve adherence and outcomes in clinical practice.

Keywords Ketogenic diet · epilepsy · adherence · barriers · dietary therapy

Citation: Ozturk, G., Akbeyaz, H., Acar, E., Ünver, O. & Türkdoğan, D. What are The Barriers to Initiating or Sustaining The Ketogenic Diet in Pediatric Patients; Single Centre Experience. Çocuk Dergisi–Journal of Child 2025; 25(2): 97-104. DOI: 10.26650/jchild.2025.1722249

Corresponding author: Gulten Ozturk ogulten2019@gmail.com

INTRODUCTION

Ketogenic diet (KD) is a well-established therapeutic option for managing refractory epilepsy in children. Classical KD has demonstrated efficacy in achieving a greater than 90% reduction in seizure frequency in approximately one-third of patients, regardless of age, seizure type, or underlying etiology, leading to significant improvements in the quality of life [1].

Despite its proven benefits in appropriately selected patients, several contraindications and practical challenges may limit its implementation in certain cases [2,3]. Classical KD requires strict dietary compliance, with meticulously measured food to ensure high fat content, minimal carbohydrate intake, and adequate protein levels [4]. For the diet to be considered effective, adherence to the treatment protocol for a minimum of 3.5 months is typically necessary [5].

Achieving and maintaining adherence require close collaboration between the patient, caregivers, and a multidisciplinary ketogenic team. This team plays a vital role in providing thorough education about diet, ongoing guidance, and continuous monitoring throughout therapy. Nevertheless, despite the increased availability of ketogenic-friendly products and robust patient–provider cooperation, studies indicate that nearly 50% of medically eligible patients referred for KD do not initiate treatment. Furthermore, up to 25% of those begin discontinuing therapy before completing the recommended three-month trial period [6].

This study aimed to explore the barriers that hinder the initiation or continuation of ketogenic diet therapy following comprehensive education delivered by an experienced ketogenic care team.

MATERIALS AND METHODS

The study was conducted with parents of patients who were referred to the Ketogenic Diet Clinic at Marmara University for educational sessions on KD, but either never initiated the diet or discontinued it within the first three months. Of 250 caregivers who received dietary education between 2014 and 2024, 140 parents who met the inclusion criteria were contacted by phone and asked to complete a survey designed to collect demographic information of the patients and identify reasons for not starting or prematurely discontinuing the diet. A total of 72 parents who agreed to participate were included in the study.

Statistical analyses were performed using SPSS version 27.0. The normality of the variable distribution was assessed using histogram plots and the Kolmogorov-Smirnov test. Descriptive statistics are presented as means, standard deviations, medians, and minimum-maximum values. Categorical variables were compared using the chi-squared test. For non-normally distributed (nonparametric) variables, comparisons between the two groups were performed using the Mann-Whitney U test. Logistic regression analysis was conducted to identify factors predicting ketogenic diet treatment status (discontinued after initiation vs. never started). In this model, the independent variables included age, age at epilepsy onset, number of siblings, seizure onset age, number of antiepileptic drugs used, total number of neurologists consulted, and number of currently involved physicians. Regression coefficients (B), p-values, odds ratios (Exp(B)), and their 95% confidence intervals were reported. Statistical significance was set at $P < 0.05$.

Ethical approval for the study was obtained from the local ethics committee (09.2025.25-0398).

RESULTS

This study included 72 patients, with an equal sex distribution of 36 females (50.00%) and 36 males (50.00%). The majority of participants (n=67, 93.06%) lived with both parents, while a smaller proportion (n=5, 6.94%) lived with parents living separately. Nearly all participants (n=69, 95.83%) were primarily cared for by their mothers, with other caregivers accounting for a very small percentage (n=3, 4.17%). Socioeconomic status, assessed based on household income, revealed that most families (n=56, 77.78%) earned above the minimum wage, whereas a notable minority (n=16, 22.22%) earned below the minimum wage. Parental employment patterns revealed that the vast majority of mothers (n=64, 88.89%) were unemployed, whereas most fathers (n=65, 90.28%) were employed. Parental education levels varied; among mothers, the largest groups were primary school and high school graduates (n=21, 29.17%), followed by university graduates (n=14, 19.44%), middle school graduates (n=11, 15.28%), and a small proportion with no formal literacy (n=5, 6.94%). Similarly, among fathers, high school graduates formed the largest group (n=23, 31.94%), followed by primary school graduates (n=19, 26.39%), university graduates (n=16, 22.22%), and middle school graduates (n=14, 19.44%). In terms of health status, a small portion of participants (n=9, 12.50%) reported the presence of a second household individual with a chronic illness other than the proband patient, while most (n=63, 87.50%) did not report any chronic conditions. For most participants, the primary diagnosis was drug-resistant epilepsy (n=69, 95.83%), with a few cases (n=3, 4.17%) having other diagnoses. Finally, regarding ketogenic diet history, more than half of the participants (n=40, 55.56%) had never initiated treatment, while a significant portion (n=32, 44.44%) had initiated but later discontinued treatment (Table 1).

Table 1. Demographic characteristics of the study group

		n	%
Gender	Female	36	(50,00)
	Male	36	(50,00)
Parental cohabitation status	Both alive and together	67	(93,06)
	Both alive and seperate	5	(6,94)
Primary caregiver	Mother	69	(95,83)
	Others	3	(4,17)
Family income	Below minmum wage	16	(22,22)
	Above minimum wage	56	(77,78)
Maternal employment status	No	64	(88,89)
	Yes	8	(11,11)
Paternal employment status	No	7	(9,72)
	Yes	65	(90,28)
Maternal education	No formal literacy	5	(6,94)
	Primary school	21	(29,17)
	Middle School	11	(15,28)
	High school	21	(29,17)
	University	14	(19,44)
Paternal education	Primary school	19	(26,39)
	Middle school	14	(19,44)
	High school	23	(31,94)
	University	16	(22,22)
Presence of other chronic disease	Yes	9	(12,50)
	No	63	(87,50)
Diagnosis	Drug resistant epilepsy	69	(95,83)
	Others	3	(4,17)
KD Treatment	Early discontinued	32	(44,44)
	Never started	40	(55,56)

The mean age of participants was 7.18 ± 4.15 years, with a median age of 6 years (range: 1 to 17 years). The mean age at epilepsy diagnosis was 4.59 ± 3.25 years, and the median was 4 years (range: 1 to 14 years). Regarding family structure, the average number of siblings was 1.63 ± 0.87, with a median of 1 (range: 1 to 4). The mean age at seizure onset was 2.58 ± 3.5 years, with a median of 1 year (range: 0 to 14 years). In terms of treatment-related data, the average number of antiepileptic drugs used was 2.74 ± 1.2, with a median of 3 drugs (range: 0 to 6). The average number of neurologists consulted per participant was relatively high at 5.54 ± 4.04, with a median of 4 (range: 1 to 20). The average number of actively involved physicians was 1.56 ± 0.82, with a median of 1 (range: 1 to 6) (Table 2).

Table 2. Characteristics of the patients related with ketogenic diet and epilepsy

	Mean±SD	Median (Min-Max)
Age at diet education	7,18±4,15	6 (1-17)
Epilepsy age	4,59±3,25	4 (1-14)
Number of siblings	1,63±0,87	1 (1-4)
First seizure age	2,58±3,5	1 (0-14)
Number of antiepileptics used during KD education	2,74±1,2	3 (0-6)
Number of neurologists consulted since initial diagnosis	5,54±4,04	4 (1-20)
Number of neurologists currently followed by	1,56±0,82	1 (1-6)

Genetic evaluation of the participants revealed that approximately half had a detected genetic abnormality (n=35, 48.61%), while the other half did not (n=37, 51.39%). During the study period, a a substantial proportion of participants experienced seizures (n=58, 80.56%), whereas a smaller percentage did not (n=14, 19.44%). In most cases, the KD was recommended by the participant's primary physician (n=67, 93.06%), with few recommendations coming from other sources (n=5, 6.94%). About half of the participants did not initiate the ketogenic diet (n=40, 55.56%), while the remaining half did (n=32, 44.44%). Among those who initiated the diet, most adhered to it for 1 to 3 months (n=19, 63.33%), while fewer followed it for less than one month (n=11, 36.67%).

When examining the occurrence of side effects during the diet, most participants did not report adverse effects (n=11, 78.57%), whereas a small portion did (n=3, 21.43%). Among those who experienced side effects, willingness to retry the diet was low (n=3, 11.54%), with most opting not to attempt it again (n=23, 88.46%).

Among participants who never initiated a diet, the most commonly reported reason was the belief that their child would be unable to adhere to it (n=15, 37.50%). Other frequently cited reasons included perceived complexity of the dietary regimen (n=8, 20.00%), a physician stating that it would be ineffective (n=5, 12.50%), and financial difficulties (n=4, 10.00%). Less frequently mentioned reasons included spontaneous seizure remission or a preference for new medications.

Among those who initiated but discontinued the diet, the most commonly cited reason was lack of therapeutic benefit (n=9, 28.13%). Other notable reasons included adverse effects (n=6, 18.75%), caregiver burden or child fatigue with dietary restrictions (n=7, 21.88%), refusal to eat ketogenic-approved meals (n=3, 9.38%), and complaints of sustained hunger (n=3, 9.38%). Less commonly reported reasons included inability to attain sustained ketosis and financial constraints (Table 3).

Table 3. Clinical features of the patients in the study group

		n	%
Identified genetic etiology	Yes	35	(48,61)
	No	37	(51,39)
Presence of active seizures currently	Yes	58	(80,56)
	No	14	(19,44)
Who referred for KD	Own doctor	67	(93,06)
	Others	5	(6,94)
Diet initiation	Yes	32	(44,44)
	No	40	(55,56)
Duration of active KD	Less than one month	11	(36,67)
	1-3 months	19	(63,33)
Side effects	No	11	(78,57)
	Yes	3	(21,43)
Would you try again?	Yes	3	(11,54)
	No	23	(88,46)
Reasons for not initiating at all	Believed that my child can not perform it	15	(37,50)
	Too challenging for me	8	(20,00)
	We two parents disagree about it	1	(2,50)
	One of our consultants did not support it	5	(12,50)
	Too expensive for our budget	4	(10,00)
	Seizure stopped before initiation of KD	3	(7,50)
	Preferred to use new antiepileptics	4	(10,00)
Reasons for early discontinuation	Did not get any benefit	9	(28,13)
	Side effects	6	(18,75)
	Could not manage to increase ketone levels	1	(3,13)
	Too expensive	2	(6,25)
	Our child lost compliance	7	(21,88)
	Did not feel satiety	3	(9,38)
	The child was resistant to food	3	(9,38)
	Others	1	(3,13)

When income levels were examined, 18.75% (n=6) of participants who initiated but later discontinued the ketogenic diet had an income below the minimum wage, compared to 25.00% (n=10) among those who never initiated the diet. Among those with income above the minimum wage, the rates were 81.25% (n=26) for those who discontinued the diet and 75.00% (n=30) for those who never initiated it. The difference in income distribution between the two groups was not statistically significant (p=0.526), suggesting that income may not be a direct determinant in the decision to initiate or discontinue the ketogenic diet.

Regarding the presence of another household member with a chronic illness, 9.38% (n=3) of participants who discontinued the diet reported a chronic condition, while this rate was 15.00% (n=6) among those who never initiated the diet. In both groups, most participants did not report any chronic disease. No statistically significant difference was found between the groups in terms of the presence of chronic illnesses (p=0.722).

In terms of seizure activity, 81.25% (n=26) of those who discontinued the ketogenic diet had seizures, compared to 80.00% (n=32) of those who did not. There was no statistically significant difference between the two groups in terms of seizure presence (p=0.894), indicating that ongoing seizures did not significantly influence the decision to initiate or stop a ketogenic diet (Table 4).

The mean age of participants who initiated but discontinued the ketogenic diet (7.66 ± 4.26 years; median: 6.5 years) was slightly higher than that of those who never initiated the diet (6.8 ± 4.06 years; median: 5 years); however, this difference was not statistically significant (p=0.339).

The groups were also similar in terms of mean age at epilepsy diagnosis (4.69 ± 3.26 years vs. 4.51 ± 3.29 years) and median values (3.5 vs. 4 years), with no statistically significant difference between them (p=0.735).

The average number of siblings was nearly identical between the two groups (1.62 ± 0.94 vs. 1.64 ± 0.82), showing no statistically significant difference (p=0.768).

Although the mean age at seizure onset was slightly higher among those who discontinued the diet (2.84 ± 3.33 years; median: 2 years) compared to those who never initiated it (2.36 ± 3.65 years; median: 1 year), the difference was not statistically significant (p=0.456).

The average number of antiepileptic drugs used was also comparable between the groups (2.91 ± 1.4 vs. 2.6 ± 1.01), with no significant difference observed (p=0.449).

Similarly, the average number of neurologists consulted was nearly identical (5.56 ± 4.59 vs. 5.53 ± 3.61), and this difference was not statistically significant (p=0.411).

No statistically significant difference was observed between the groups in the number of actively involved physicians (p=0.273) (Table 5).

Table 6 presents the results of a logistic regression analysis conducted to identify factors predicting whether patients initiated and later discontinued ketogenic diet therapy or never initiated it at all. The analysis examined the effects of variables such as age, age at epilepsy onset, number of

siblings, age at seizure onset, number of antiepileptic drugs used, total number of neurologists consulted, and number of actively involved physicians.

According to the logistic regression results, none of the evaluated demographic or clinical variables (age, age at epilepsy onset, number of siblings, age at seizure onset, number of antiepileptic drugs, total number of neurologists consulted, and number of actively involved physicians) significantly predicted whether a patient discontinued or never initiated ketogenic diet therapy. For all variables, the p-values were greater than 0.05.

The regression coefficient (B) for age was 0.051 with a p-value of 0.383. Exp(B) was 1.052, with a 95% confidence interval of 0.939–1.178, indicating no significant effect of age on decisions regarding ketogenic diet therapy.

For age at epilepsy onset, the B coefficient was 0.017 (p=0.821), Exp(B) was 1.017, and the confidence interval ranged from 0.880 to 1.175, indicating that this variable was also not a significant predictor.

The number of siblings had a B value of −0.028, p=0.926, Exp(B)=0.972, and a confidence interval of 0.535–1.767, indicating no meaningful impact.

The age at seizure onset had a B coefficient of 0.040 and a p-value of 0.560, with Exp(B)=1.041 and a confidence interval of 0.910–1.191. This suggests that the age at seizure onset was not a significant factor influencing dietary decisions.

For the number of antiepileptic drugs used, the B value was 0.220, with a p-value of 0.282, Exp(B)=1.246, and a confidence interval of 0.835–1.859, indicating no statistical significance.

The total number of neurologists consulted had a B coefficient of 0.002, p=0.969, Exp(B)=1.002, and a confidence interval of 0.893–1.125, supporting the conclusion that this variable had no significant effect on dietary decisions.

Finally, the number of actively involved physicians had a B coefficient of −0.476, p=0.180, Exp(B)=0.621, and a confidence interval of 0.310–1.246, again showing no statistically significant predictive value.

Table 4. Impact of comorbid factors on initiation and continuation of ketogenic diet

		KD				
		Early discontinued		Never started		
		n	%	n	%	P*
Family income	Below minmum wage	6	(18,75)	10	(25,00)	0,526
	Above minmum wage	26	(81,25)	30	(75,00)	
Presence of chronic disease	Yes	3	(9,38)	6	(15,00)	0,722
	No	29	(90,63)	34	(85,00)	
Presence of active seizures currently	Yes	26	(81,25)	32	(80,00)	0,894
	No	6	(18,75)	8	(20,00)	

*Chi-square test

Table 5. Impact of clinical and neurological factors on initiation and continuation of ketogenic diet

	KD				
	Early discontinued		Never started		
	Ort±s.s	Medyan (Min-Max)	Ort±s.s	Medyan (Min-Max)	p
Current age during KD education	7,66±4,26	6,5 (1-17)	6,8±4,06	5 (1-16)	0,339
Epilepsy age	4,69±3,26	3,5 (1-14)	4,51±3,29	4 (1-13)	0,735
Siblings	1,62±0,94	1 (1-4)	1,64±0,82	1 (1-3)	0,768
Initial seizure age	2,84±3,33	2 (0-11)	2,36±3,65	1 (0-14)	0,456
Number of antiepileptics during KD education	2,91±1,4	3 (0-6)	2,6±1,01	3 (0-4)	0,449
Number of neurologists consulted since initial diagnosis	5,56±4,59	3,5 (1-20)	5,53±3,61	5 (1-20)	0,411
Number of neurologists actively followed by	1,41±0,56	1 (1-3)	1,68±0,97	1 (1-6)	0,273

Mann Whitney-U Test

Table 6. Logistic regression analysis of factors affecting initiation or continuation of ketogenic diet

	B	p	Exp(B)	95% C.I.for EXP(B)	
				Lower	Upper
Current age during KD education	0,051	0,383	1,052	0,939	1,178
Epilepsy age	0,017	0,821	1,017	0,880	1,175
Presence of siblings	-0,028	0,926	0,972	0,535	1,767
First seizure age	0,040	0,560	1,041	0,910	1,191
Number of current antiepileptics during KD education	0,220	0,282	1,246	0,835	1,859
Number of consulted neurologists since initial diagnosis	0,002	0,969	1,002	0,893	1,125
Number of neurologists actively followed by	-0,476	0,180	0,621	0,310	1,246

Logistic Regression

DISCUSSION

This study investigated the barriers to initiation and reasons for early discontinuation of ketogenic diet therapy (KDT), along with associated demographic and clinical variables.

The successful implementation of the ketogenic diet largely depends on coordinated support from the healthcare team, collaboration with social and educational services, and active family participation. Owing to its restrictive nature and potential side effects, the diet requires close medical supervision and comprehensive nutritional management [7,8].

Our findings revealed that only 44% of the patients who received thorough education on the ketogenic diet at our center were initiated. Among these, 29% discontinued therapy within three months. These results align with the existing literature, which indicates that approximately 50% of patients referred for KDT do not begin treatment, and approximately 25% discontinue treatment shortly after initiation [2,9].

Common motivational barriers include doubts about the diet's efficacy, its complexity, and caregiver fatigue, all of which are well-documented in the literature as impediments to initiation [6]. Similarly, in our cohort, the predominant reason for not initiating a diet was the belief that the child would not tolerate or adhere to it. Other reported reasons included perceived ineffectiveness, concerns about adherence, caregiver burden, and, to a lesser extent, financial costs, which is consistent with previous studies [2,8,10].

Interestingly, logistic regression analysis revealed no statistically significant associations between non-initiation and demographic or clinical factors, such as age, epilepsy duration, number of antiepileptic drugs, or socioeconomic status. Larger-scale studies with broader cohorts are needed to better understand the influence of these factors by comparing patients who adhere to KDT with those who do not initiate or discontinue KDT.

While KDT can be implemented across all age groups, from infancy to adulthood, previous studies have reported the highest adherence rates in children under five years, with reduced compliance in adolescents [11]. In our study, age was not a determining factor for either non-initiation or discontinuation. The median age across both groups was approximately five years, reinforcing that concerns beyond age were more prominent in our cohort.

Although seeking secondary opinions is generally beneficial in managing chronic illnesses, excessive specialist consultations may create confusion and hinder treatment consistency. Our study found that the median number of specialists consulted per patient (median, 4) was significantly higher than the global average. For patients who did not initiate KDT, discouragement from another physician was a key factor. This fragmentation in care can undermine trust in primary care providers, potentially compromising the consistency and effectiveness of ketogenic management [12,13].

In line with the COM-B (Capability, Opportunity, Motivation-Behavior) framework, our findings underscore the importance of addressing motivational and contextual barriers during the decision-making process. Strategies such as simplifying dietary protocols, offering culturally appropriate food options, and ensuring multidisciplinary support could enhance motivation and promote long-term adherence [2].

Cost-effectiveness plays a critical role. Implementing and sustaining a diet with a minimal financial burden is essential for both initiation and continuation. Ketone and glucose monitoring devices, additional vitamin supplements, and certain specialized foods used in the ketogenic diet may impose an extra financial burden during its implementation. In our study, 22% of the participants reported low income; however, this factor did not show a statistically significant impact on initiation or adherence, suggesting that while financial limitations are relevant, they may not be primary determinants [8].

Although side effects are a commonly cited concern, many are transient and manageable under expert supervision, reinforcing the safety and efficacy of KDT for epilepsy [14,15]. In our cohort, 18% of patients who discontinued early treatment attributed this to side effects, although they also reported perceived ineffectiveness. A therapeutic response that falls below expectations may reduce motivation among both caregivers and healthcare providers, limiting efforts to manage side effects and continue the diet.

Time constraints, often due to busy schedules, are also frequently reported as obstacles to adherence [16,17]. In our cohort, most mothers— primary caregivers) were unemployed. Notably, maternal employment status did not influence the decision to initiate a diet. This suggests that, regardless of employment, caregivers likely require substantial support to successfully initiate and maintain a ketogenic diet [18,19].

Limitations of the study

Since the study was conducted using a pre-designed questionnaire to retrospectively collect information, the likelihood of reduced recall accuracy increases as the time elapsed between the education session and the time of the study lengthens.

CONCLUSION

Although the clinical efficacy of KDT has been well established through randomized controlled trials, its real-world effectiveness is often challenged by practical barriers to implementation [8,9]. Our findings emphasize that successful outcomes with KDT depend less on clinical eligibility and more on the family's capacity to incorporate the regimen into daily life. Despite its restrictive demands, many families demonstrate strong willingness and often impressive adherence [10,17].

As the number of centers offering specialized ketogenic diet services continues to grow, it is essential to design educational and follow-up programs that account for potential barriers to both initiation and long-term compliance. Doing so will significantly enhance the success rate of ketogenic diet therapy in clinical practice.

Ethics Committee Approval: Ethical approval for the study was obtained from the local ethics committee (09.2025.25-0398).
Informed Consent: Written consent was obtained from the participants.
Peer Review: Externally peer-reviewed.
Author Contributions: Conception/Design of Study- G.Ö., H.A., E.A.; Data Acquisition- G.Ö., H.A., E.A; Data Analysis/Interpretation-G.Ö. ; Drafting Manuscript- G.Ö.; Critical Revision of Manuscript- O.Ü., D.T.; Final Approval and Accountability- G.Ö.,D.T.,H.A., E.A., O.Ü.
Conflict of Interest: Authors declared no conflict of interest.
Financial Disclosure: Authors declared no financial support.

Author Details

Gulten Ozturk
[1] Marmara University Pendik Education and Research Hospital, Pediatric Neurology,Istanbul, Türkiye
0000-0003-4582-5121 ogulten2019@gmail.com

Hakkı Akbeyaz
[1] Marmara University Pendik Education and Research Hospital, Pediatric Neurology,Istanbul, Türkiye
0000-0001-6400-2775

Ebru Acar
[2] Marmara University Pendik Education and Research Hospital, Nutrition and Dietetics,Istanbul, Türkiye
0009-0007-0662-0891

Olcay Ünver
[1] Marmara University Pendik Education and Research Hospital, Pediatric Neurology,Istanbul, Türkiye
0000-0003-3035-7433

Dilşad Türkdoğan
[1] Marmara University Pendik Education and Research Hospital, Pediatric Neurology,Istanbul, Türkiye
0000-0002-6607-5860

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