Evaluation of the Knowledge Level, Practice and Attitudes of the Caregivers on Ketogenic Diet Management

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Cite this article as: Bayram S, Çalışkan H. Evaluation of the knowledge level, practice and attitudes of the caregivers on ketogenic diet management. *Arch Epilepsy.* 2022;28(1):23-28.

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Abstract

Objective: Patients with intractable childhood epilepsy may benefit from ketogenic diet treatment. Management of ketogenic diet depends on the knowledge level and practice and attitudes of their caregivers. Although advances have been made on early diagnosis and treatment options, there is still a lack of knowledge in children with epilepsy and their caregivers.

Methods: In the study, 40 voluntary individuals caring for a child with intractable childhood epilepsy who is under a ketogenic diet were included. The visual analog scale was used to determine adherence to the ketogenic diet for both caregivers and children. Dietary adherence of young children (<10 years) was assessed by the caregiver. Ketogenic diet knowledge of caregivers was determined to form with 40 questions (free/prohibited foods, meal contents, any form of carbohydrate sources, label reading, side effect awareness, and management practices).

Results: Availability of ketogenic products, feeling of hunger, frequent glucose, and ketone measurement were determined to be the most difficulties in adherence to the ketogenic diet. According to the visual analog scale results, the mean knowledge level of the caregivers was 3.55 ± 3.67 , ketogenic diet adherence was 7.52 ± 2.40 for the caregivers, and 8.42 ± 1.62 for the patients. 25% of the caregivers have high, 65% of them have low knowledge. The number of antiepileptic drugs used decreased. The number of seizures per week was 32.65 ± 21.15 before the ketogenic diet, it decreased to 21.54 ± 15.69 .

Conclusions: The effectiveness of the ketogenic diet was better in medium and high knowledge levels. As the competence increases, ketogenic diet management will be easier. Therefore, it would be beneficial to visit a dietitian during clinic visits and to seek answers to food-related problems.

Keywords: Attitudes, caregiver, intractable childhood epilepsy, ketogenic diet, knowledge

INTRODUCTION

Epilepsy is a disease characterized by recurrent epileptic seizures and behavioral or motor functions as a result of electrical discharges in the brain.¹ The worldwide prevalence of active epilepsy is estimated to be 0.8-1%.² While the majority of childhood epilepsy patients can be treated with antiepileptic drugs, 25-30% of them have intractable childhood epilepsy (ICE). In that type of epilepsy, despite the use of multiple antiepileptic drugs the seizures cannot be prevented.³ Patients with ICE may benefit from surgery, vagus nerve stimulation, or ketogenic diet (KD) treatment.⁴⁻⁸ Classic KD has been used to treat epilepsy since 1921 and its use has been increasing in recent years.^{9,10} All ketogenic diet types include fat as 65-90% of the daily energy requirement.⁷ In classical KD, the ratio of fat to carbohydrate and protein in grams is 4 : 1 (approximately 90% of total energy is fat).¹¹ In infants, young children, and adolescents; 3 : 1 (86% fat) and 2 : 1 (83% fat) ratios are also used to provide adequate protein and prevent hypoglycemia.¹² Alternative and more flexible KD derivatives [medium chain triglyceride diet, modified Atkins diet, and low glycemic index diet] have been developed which have fewer side effects, are easier to apply, and make the diet more palatable for ICE patients.^{8,9} Since these diets are more flexible, higher compliance and acceptability have been reported by patients and their caregivers.^{13,14} Families and/or caregivers should be educated regularly about KD to ensure adherence.^{15,16}

Due to the myths and misunderstandings about the benefits and side effects of the KD, and also the lack a sufficient number of trained physicians and dieticians, it is rarely applied.^{17,18} All types of KD require training and motivation of patients and caregivers to understand complex instructions such as weighing foods and tracking ketone levels. Therefore, adherence to KD is lower in children of parents with low education levels and poor socioeconomic status. Adherence to KD is highest especially in patients whose seizures decreased by more than 50% in the first weeks.⁸

Although advances in the early diagnosis and treatment options, there is still a lack of knowledge in children with epilepsy and their families.^{5,19} Recent studies found that traditional treatment methods are the first preferred methods by families in childhood epilepsy in different cultures.²⁰ Knowledge, attitudes, and perceptions about epilepsy of caregivers are affected by the severity and frequency of seizures and have a great impact on children's daily life.^{5,21} In a study conducted on patients with epilepsy found that the education level of caregivers is generally low, and therefore, their knowledge about the disease and treatment is also low.²² Management of disease in children with ICE largely depends on the attitudes of their caregivers. However, it is observed that the majority of the families and society do not have accurate information about the effectiveness of diet on ICE.²³⁻²⁶ While there are more studies in the literature regarding the effectiveness of the KD, no study has been found in which the knowledge level, practices, and attitudes of the caregivers on KD management are questioned. Thus, this research is aimed to determine the knowledge level, practices, and attitudes of caregivers about the KD in ICE.

METHODS

The study was conducted on children and adolescents with ICE who applied to the pediatric neurology outpatient clinic of a public hospital in Ankara, Turkey between September 2019 and December 2019. Available 40 individuals caring for a child/adolescent with ICE who is on classic KD therapy and willing to answer questions for the study was included for the study. In KD therapy, to provide enough protein, ratios of 3 : 1 (86% fats) and 2:1 (83% fats) can be preferred in adolescents, children, and infants.

Children and adolescents with any other systemic disease except ICE were excluded. This study was approved by Başkent University Medical and Health Sciences Research Board (project number: KA18/168) and supported by Başkent University Research Fund (Date: May 29, 2018).

In this descriptive study, we questioned sociodemographic characteristics such as age, gender, educational status, etc. of both child and caregivers. Also, disease-related factors such as epilepsy age, antiepileptic drugs and KD ratio (the ratio of fat to carbohydrate plus protein in grams), questions about KD treatment (training period, adherence, seizure frequency, forbidden foods/non-nutritional sources, diet management, side effect awareness, etc.) were questioned. The questionnaire was applied by the researchers using face to face interview method.

A VAS from 1 to 10 was used to determine the adherence of KD both caregivers and children. Dietary adherence of young children (<10 years) was assessed by the caregiver. Caregivers were also asked to evaluate their own knowledge of KD with VAS. Visual analog scales are a standardized and validated system of assessment that requires a response to questions such as "How adherer do you think you are to ketogenic diet? How sufficient is your level of knowledge about the ketogenic diet?" to be marked on a line (100 mm in length) anchored at each end with opposing statements such as "Not at all" and "Extremely."

Ketogenic diet knowledge of caregivers was determined by a form with 40 questions (free and/or prohibited foods, meal contents, any form of carbohydrate sources, label reading, side effect awareness, and management practices). This form was applied to the one who prepares the ketogenic meals. Each correct answer was evaluated as 1 point and a total of 0-40 points can be obtained. Accordingly, low knowledge level is evaluated as below 20 points, moderate knowledge level as 20-30 points, and high level of knowledge as 30 points and above. The efficacy of the KD was accepted as a greater than 50% reduction in the frequency of seizures.

Statistical Analysis

The data were analyzed with the Statistical Package for the Social Sciences Version 21.0. (IBM SPSS Corp.; Armonk, NY, USA). Continuous variables are presented with mean (X) and standard deviation. Frequency (S) and percentage (%) values were used for the presentation of categorical variables. Whether the parametric test conditions were met in comparing means was investigated by Kolmogorov–Smirnov test. Paired sample *t*-test and independent sample *t*-test were

used where appropriate. In all statistical analyzes, the level of significance was accepted as P < .05.

RESULTS

The study was carried out with 40 caregivers of a child or adolescent with ICE who applied to the Neurology Polyclinic in a public hospital in Ankara. The socioeconomic and demographic characteristics of the patients and caregivers are given in Table 1. Accordingly, 57.5% of the patients were boys, almost all caregivers were mothers and 62.5% of the mothers had less than high school education level. The mean age of the mothers and the children was 31.87 ± 7.07 and 5.48 ± 2.99 years, respectively.

The duration, effectiveness, and side effects of KD therapy are shown in Table 2. Accordingly, the mean KD duration was determined to be 9.60 ± 8.34 months. Based on individual tolerance and/or level of ketosis, different KD ratios were used in our study (2 : 1 and 4 : 1).

Only 10% of the children had 4 : 1 ratio which is the hardest type of KD. Ketogenic diet stopped seizures in 27.5% of the patients and the effectiveness of KD on seizures was determined in about half of the patients within 1 month. Constipation was the most common side effect of KD.

Ketogenic diet practices and attitudes of caregivers are shown in Table 3. A total of 65% of caregivers found KD education inadequate,

 Table 1. Socioeconomic and Demographic Characteristics of the Patients and Caregivers

	n	%
Gender of child		
Female	17	42.5
Male	23	57.5
Socio-economic status		
Low	19	47.5
Middle-high	21	52.5
Consanguineous marriage		
Yes	29	72.5
No	11	27.5
Family history of epilepsy		
Parents or siblings	3	7.5
Other relatives	6	15.0
No	31	77.5
Caregiver		
Mother	39	97.5
Grandmother	1	2.5
Educational status of mothers		
Less than high school	25	62.5
High school graduate	7	17.5
4-year college degree	7	17.5
Masters, doctoral	1	2.5
Working status of mothers		
Working	4	10.0
Non-working	36	90.0
	Mean	SD
Age, years, mothers	31.87	7.07
Age, years, children	5.48	2.99
Time since diagnosis, years	4.67	3.40
SD, standard deviation.		

Table 2. Descriptives of Ketogenic Diet

	Mean	SD
Duration since KD started, months	9.60	8.34
	n	%
Ratios		
2/1	9	22.5
2.5/1	15	37.5
3/1	12	30.0
4/1	4	10.0
Effectiveness		
No seizures	11	27.5
1-2 seizures per week	4	10.0
3-4 seizures per week	5	12.5
Per day	4	10.0
Shortened seizure duration	5	12.5
Not effective	11	27.5
Duration between effectiveness and beginning of KD, months	g	
1	19	47.5
2	1	2.5
3	6	15.0
6	2	5.0
9	1	2.5
Decreased symptoms after KD*		
Hyperactivity/attention deficit	9	22.5
Aggresive behavior/anger outbursts	9	22.5
Insomnia	5	12.5
Anorexia	5	12.5
Hypersalivation	5	12.5
Urinary incontinence	4	10.0
Eye twitching	3	7.5
Hand tremors	2	5.0
Side effects after KD*		
Constipation	21	52.5
Hypoglycemia	12	30.0
Vomiting	7	17.5
GORD	3	7.5
Kidney stones	4	10.0
Abdominal pain	3	7.5
Dyslipidemia	7	17.5

and 45% of them had less than 1 hour of KD education. Multivitamins (37.5%), vitamin D (35%), and fish oil/omega-3 fatty acids (30%) were found to be the most preferred dietary supplements.

Availability of ketogenic products, feeling of hunger, frequent blood glucose monitoring, and frequent ketone measurement were determined to be the most difficulties in adherence to the KD.

Ketogenic diet knowledge of caregivers and adherence to diet are given in Table 4. According to the VAS results, the mean knowledge level of the caregivers was 3.55 ± 3.67 , KD adherence was 7.52 ± 2.40 for the caregivers, and 8.42 ± 1.62 for the patients. While 25% of the caregivers have high KD knowledge, 65% of them have low KD knowledge. While the KD was found to be effective in 85.7% of the children in the group with moderate-high caregiver knowledge, it was effective only in 30.8% of the children in the group with low caregiver knowledge.

	n	%
Adequacy of KD education		
Yes	14	35.0
No	26	65.0
Educationalist		
Dietitian	14	35.0
Physician	12	30.0
Nurse	2	5.0
Multidisciplinary team	12	30.0
Duration of education		
≤60 minutes	18	45.0
60-120 minutes	6	15.0
120-180 minutes	10	25.0
≥180 minutes	6	15.0
Preferred nutritional supplements*		
Fish oil/omega-3 fatty acids	12	30.0
Black cumin seed	6	15.0
Wheat germ oil	6	15.0
Vitamin D	14	35.0
Probiotics	10	25.0
Multivitamins	15	37.5
Purposes to use nutritional supplements		
Reducing side effects	2	5.0
Meeting the nutritional requirements	10	25.0
Increasing nutrient utilization	12	30.0
Difficulties of KD*		
Frequent blood glucose monitoring	13	32.5
Frequent ketone measurement	12	30.0
Availability of ketogenic products	17	42.5
Feeling of hunger	14	35.0
Weighing food	5	12.5
Product cost	10	25
Forbidden food management	5	12.5
Methods of controlling forbidden food intake*	2	15.4
Locking the kitchen door	2 4	15.4
Never eating without asking caregivers	4	30.7 30.7
Never learning food outside	4	
Never keeping forbidden food at home Awareness about food labels	6	15.4
		46.1
Social environment education about KD	3 2	23.0 15.4
Consuming olive oil after forbidden food intake	Z	13.4
Practices in case of refusal to eat*	7	17.5
Encouragement	2	5.0
Freezing and serving as a drink Lead to self-eating	2 3	5.0 7.5
Insist of eating	12	30.0
Waiting and then trying again	12	30.0
Mixing with favorite food	5	12.5
*Multiple responses.	5	12.3

Comparison of the used anti epileptic drugs (AEDs) and number of weekly seizures before/after KD therapy and knowledge level of the caregivers are shown in Table 5. Accordingly, the number of AEDs used after KD decreased (P > .05). While the number of seizures per week was 32.65 ± 21.15 before KD, it decreased to 21.54 ± 15.69 after KD (P < .05). The number of AEDs (P > .05) and weekly seizures (P < .05) were higher in the group with low caregiver knowledge.

	Μ	ean	S	SD	
Caregivers KD knowledge (VAS 0-10)	3	.55	3	.67	
Caregivers KD adherence (VAS 0-10)	7.52		2.40		
Patient KD adherence (VAS 0-10)	8.42		1.62		
Caregivers KD knowledge (0-40 score)	15.85		13.90		
	n		%		
High (≥30 score)	10		25.0		
Moderate (20-30 score)	4		10.0		
Low (≤20 score)	26		65.0		
	Moderate-High Knowledge Level		Low Knowledge Level		
Effectiveness of KD	S	%	S	%	Р
Effective	12	85.7	8	30.8	.001 ($\chi^2 = 10.989$)
Not effective	2	14.3	18	69.2	

KD, ketogenic diet; SD, standard deviation; VAS, visual analog scale.

DISCUSSION

In this study, the mean age of the mothers and children were 31.87 ± 7.07 and 5.48 \pm 2.99, respectively. Children who participated in the study had at least 1 up to an 8-year history of epilepsy and they had been on a KD treatment for almost the last 9.6 months. In a similar study of 48 children and adolescents who were diagnosed with ICE between the ages of 8 months to 17 years, the KD was started a mean of 23 months (4.5 months-8 years) after the diagnosis of epilepsy, half of the participants were on the classic KD and 33% of them on MCT-KD and 17% of them on modified Atkins diet.²⁷ Since our study group has a wide age range including very young children and adolescents, we evaluated the KD ratios we could apply in our study. Only 10% of our patients could tolerate a KD ratio of 4/1.

The effectiveness of KD includes >50% reduction in seizures and reduction or cessation of AEDs within 3 months of starting the diet.²⁷ In this study, after ketogenic diet therapy, no epileptic seizure was observed in 27.5% of the patients, while less than 4 seizures weekly were observed in 25% of the patients. However, 27.5% of the patients had reported no effect was observed on seizures after KD therapy. The effectiveness of the KD was observed in 47.5% of the patients within the first month, and in the first 3 months in 65%. Wibisono et al²⁷ reported in their

Table 5. Comparison of the AEDs Used and the Number of Weekly Seizures by Before and After KD and Knowledge Level of Caregivers About KD

0	8 8		
Before KD	After KD		
Mean ± SD	$Mean \pm SD$	Р	
3.57 ± 1.48	3.35 ± 1.89	.291 [¤]	
32.65 ± 21.15	21.54 ± 15.69	.002 ^{**}	
Moderate-high knowledge level	Low knowledge level		
2.40 ± 1.77	3.66 ± 1.84	.065¥	
18.92 ± 12.65	24.56 ± 14.13	.034 ^{¥*}	
	Mean \pm SD 3.57 ± 1.48 32.65 ± 21.15 Moderate-high knowledge level 2.40 ± 1.77	Mean \pm SD Mean \pm SD 3.57 ± 1.48 3.35 ± 1.89 32.65 ± 21.15 21.54 ± 15.69 Moderate-high knowledge level Low knowledge level 2.40 ± 1.77 3.66 ± 1.84	

^oPaired sample *t*-test; [¥]independent sample *t*-test; **P* < .05.

KD, ketogenic diet; SD, standard deviation; AEDs, antiepileptic drugs.

Bold font indicates statistical significance.

study that children were administered the classic KD for 16 months (11-24 months), MCT KD for 24 months (12-27 months), and modified Atkins diet for 12 months (3-24 months). According to the results of the study mentioned, 6% of the children were seizure-free, 29% had >90% reduction, 43% had >50-90% reduction, and 11% had >25-50% reduction. In one study, KD treatment helped reduce seizures by at least 50% in more than half of the children, while 10-15% of them became seizure-free.²⁸ Handerson et al¹⁶ evaluated 1084 children with a mean age of 5.78 ± 3.43 years in a meta-analysis including 19 studies. A decrease of more than 90% in seizures of one-third of children and a decrease of more than 50% was observed in half of the children.

Kossof et al²⁹ stated that the most common reason for starting KD was to decrease the number of seizures, to improve cognitive state, and to reduce the AEDs used.²⁹ Complications such as hyperactivity/attention deficit, aggressive behavior, insomnia, and anorexia were found to decrease with KD therapy in this study. However, constipation was the most common side effect (52.5%), side effects such as hypoglycemia, dyslipidemia, vomiting, gastroesophageal reflux disease, kidney stones, and abdominal pain were also observed. It is well known that constipation is the most common (50-65%) side effect of KD, and side effects such as hypertriglyceridemia, hypercholesterolemia, diarrhea, lethargy, iron deficiency, pancreatitis, persistent-severe vomiting, and hypoglycemia are also common.^{1,27,30}

In order to ensure the effectiveness of KD, families and children should be trained by a multidisciplinary team consisting of dieticians, doctors, nurses, and social workers before starting the diet. The KD is an important intervention that requires daily strict adherence, thus practical training is very important.³¹ The content of the training should include information about the prohibitions and the effectiveness of the diet, and the expectations of the family should be determined. Many families expect not only a reduction in seizures but also a reduction in AEDs and cognitive improvement. However, the team must keep the expectations realistic for each child. The family should know what difficulties they may face in both the short and long terms, such as possible nausea, vomiting, and various medical complications, and how to cope with these problems if they are seen. Parents should be given a primary decision-making role in deciding the continuation of KD for their children unless there are obvious medical concerns. The timing and the actual method of cessation of KD treatment are usually customized according to the patient's response to the diet.11

The consensus report published by the International Ketogenic Diet Study Group in 2018 suggested that the KD should be followed for at least 3 months to decide whether it is effective. Therefore, most parents are advised to continue KD for at least 3 months, even if it appears to be ineffective.⁸ In this study, 35% of the caregivers were trained by a dietician, 30% by a doctor, and 30% by a multidisciplinary team, but 65% of the caregivers found the training given inadequate. Kossof et al²⁹ reported the doctor was declared as the most common source of information (72%) about KD, and the internet was the second. Moreover, approximately 10% of patients obtained information from a dietician before starting KD.

While can be achieved with a balanced diet, vitamin and mineral supplementation is required as the KD is restricted to fruits, vegetables, grains, and dairy products. Children with ICE who receive KD therapy often have low vitamin D and calcium levels. Vitamin B supplementation may be needed in particular.¹² In the current study, 37.5% of the children were using multivitamin supplements, 35% vitamin D, and 30% omega-3 supplements. In addition, the use of probiotics, black cumin, and wheat germ oil was observed in this study group. In a recent study, multivitamins were identified as the most commonly used supplements, and it was noted that potassium citrate, vitamin D supplemented calcium, iron, zinc, and fish oil supplements were also used.²⁷

Children who are on KD therapy should be monitored by a dietician and pediatric neurologist at intervals of at least 3 months.^{11,12} According to our results, the most common difficulty in practicing KD for caregivers is the low availability of ketogenic products. In addition, the feeling of hunger, frequent blood glucose and ketone level measurement, food weighing, ketogenic product cost, and management of forbidden foods were also identified as difficulties in KD practice. Similar to our results, studies also reported difficulties such as low availability of ketogenic products, financial factors such as cost of food or insurance denial, lack of time for food preparation and cooking, and avoidance of social eating like individuals with standard diets.^{1,29,32,33}

In this study, caregivers use methods such as reading food labels carefully, not consuming any food without consulting the caregiver, not consuming any food from outside, and/or explaining KD to the social environment in order to control dietary breaks. Non-adherence to diet is one of the most important contraindications of KD.¹ In our study, the knowledge level of the caregivers about KD and the adherence to KD for both caregivers and patients were determined.

According to our results, 3 out of 4 caregivers had a low and moderate level of KD knowledge.

Churuangsuk et al³³ separated 170 adults groups like current followers, past followers, and non-followers of low carbohydrate diets in a sample of the UK population. They stated that the median carbohydrate knowledge score was the lowest in the current low carbohydrate diet followers.³³ In a study conducted with Turkish children between the ages of 11-16 who do not have epilepsy to determine the knowledge, perception, and attitudes toward epilepsy, 23% of children describe food as one of the conditions that trigger seizures.²³ Similarly, in a study conducted in South Korea, the knowledge about epilepsy and its treatment was questioned in individuals who neither have epilepsy nor the relative with epilepsy. According to the results of that study, 20% of the participants thought that some foods can reduce the symptoms of epilepsy and also stated that alcohol, cigarettes, coffee, high-fat, and high-calorie content diets should be avoided.²⁴ Cessation of AEDs is one of the main goals of KD and the reduction in the number of seizures is reported as one of the most important factors affecting dietary compliance.^{12,27} In this study, the number of AEDs after KD was insignificant and the number of weekly seizures decreased significantly. The use of AED in children of families with a medium and high level of CD knowledge was insignificant, and the number of seizures per week was significantly decreased compared to those with a low level of knowledge. In a study, 4.8 (min-max 1-14) AED per day was used before starting dietary treatment in children, while this number decreased to 2.1 (min-max 0-5) with diet.²⁹ Wibisono et al²⁷ while the number of AEDs decreased in 38% of children with CD, there was no change in 46% of them.

In conclusion, our study determined that the effectiveness of the KD increased in the group with medium and high KD knowledge levels. It is thought that as the competence about the KD increases, management will be easier. Therefore, it would be beneficial for those receiving KD therapy to visit a dietitian during their clinic visits and to seek answers to all their food-related problems.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Başkent University Medical and Health Sciences Research Board (Date: May 29, 2018, Decision no: KA18/168).

Informed Consent: Written informed consent was obtained from patients who participated in this study.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept: S.B.; Design: S.B.; Supervision: S.B.; Data collection &/or processing: S.B., H.Ç.; Analysis and/or interpretation: S.B., H.Ç.; Literature search: H.Ç.; Writing: S.B., H.Ç.; Critical review: S.B.

Declaration of Interests: The authors have no conflicts of interest to declare.

Funding: The authors declared that this study has received no financial support.

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