

Nursing Approaches in Pediatric Epilepsy and Ketogenic Diet Treatment

Tansel Çalhık¹, Ünsal Yılmaz² and Aycan Ünalp^{3*}

¹*Ketogenic Diet Nurse, Health Sciences University, Dr. Behçet Uz Childrens Disease and Pediatric Surgery Training and Research Hospital, İzmir, Turkey*

²*Associated Professor, Health Sciences University, Dr. Behçet Uz Childrens Disease and Pediatric Surgery Training and Research Hospital, Department of Pediatric Neurology, İzmir, Turkey*

³*Professor, Department of Pediatric Neurology, Health Sciences University, Dr. Behçet Uz Childrens Disease and Pediatric Surgery Training and Research Hospital, İzmir, Turkey*

***Corresponding Author:** Aycan Ünalp, Professor, Department of Pediatric Neurology, Health Sciences University, Dr. Behçet Uz Childrens Disease and Pediatric Surgery Training and Research Hospital, İzmir, Turkey.

Received: June 23, 2020; **Published:** July 17, 2020

Abstract

Epilepsy, which is one of the oldest neurological diseases known by mankind and still continues to occur frequently; It is a situation in which the wrong approach and behaviors can be done with panic, which is characterized by recurring seizures, which causes fear in the family and even health personnel. Same time; It is a disease that requires being prepared for physical changes, compliance with daily medication use, attention, recurrent doctor examinations and acute medical emergencies and increases the problems of patients by adversely affecting the quality of life. Research shows that families with children with epilepsy disease do not have enough information about the disease and its treatment.

Current research has led to a better understanding of the role of nurses in education of patients with epilepsy. These investigations and observations; From the diagnosis of the disease, acceptance, learning of drug use, continuous and regular use, and understanding of the factors that trigger seizures, it has shown that families need to learn everything from first intervention in seizures to nutrition and adaptation to the environment. For this reason, the treatment of epilepsy patients should be continued with a regularly established team. In addition, the follow-up of an experienced team of physicians, dieticians and nurses will enable the treatment safety and success of the ketogenic diet.

Establishing a good bond with the patient and the family increases the success of the ketogenic diet. It is necessary to establish good communication between patients, families and nurses in order to improve the quality of life and to solve psychosocial problems of children and families with epilepsy.

Keywords: Epilepsy; Childhood; Nursing Approaches; Ketogenic Diet

Introduction

Epilepsy is one of the earliest neurological diseases known to mankind and continues to be very common. It is a condition characterized by recurrent seizures, arousing a sense of fear in family and even healthcare personnel. Epilepsy can be seen in all ages and races, regardless of social class. It is estimated that 50 million people in the world are suffering from epilepsy [1,2].

Epilepsy is a disease that requires patients to, change behaviour and daily habits including sleeping, eating, and social activities, and also patients should pay attention in daily drug use, repeated medical examinations and acute medical emergencies these changes affect quality of life adversely [3]. The aim of epilepsy treatment is to reduce or control the frequency and severity of seizures, to recognize and treat the cause of the seizure whenever possible, and to help the child maintain his normal life [4]. Previous investigations have shown that families of children with epilepsy do not have enough information on disease and disease treatment [5-7]. Epilepsy also has adverse effects on the quality life of the patient's family. It is not easy to for parents to accept their children have a diagnosis of epilepsy. Epilepsy causes an important psychological problem on the patient's family [8,9]. Mothers of epileptic patient may also feel guilty and embarrassed by linking between their children's epilepsy and doing something wrong in their pregnancy [10].

Nursing approaches in pediatric epilepsy

In developed countries such as Denmark, public awareness about epilepsy has been found to be effective in correcting negative behaviors. It is pointed out that negative behaviors are observed in developing countries where education is limited [11]. Understanding the role of nurses in education through new research has led to a better understanding of the changing face of epilepsy and epileptic patients [12]. In these surveys and observations, it has been shown that education about epilepsy was very important for the families to accept diagnosis of epilepsy to learn how necessary to take medications regularly and to know about factors which may precipitate seizures including sleep deprivations, flash lights, alcohol etc. For this reason, the treatment of epilepsy patients should be carried out with a regular team.

Patient education is aimed to give knowledge, attitude and skills to patients and their families. The doctor that makes diagnosis arranges the treatment and explains how to use medicines. The first intervention is important in seizures and the patient care-givers must be informed adequately by the team members. The most suitable ones for this issue are the nurses who deal with the patient. Nurses have a critical role in ensuring the best health conditions for epileptic patients. Patient education includes information about the disease, learning of self-management skills and discussion of treatment options. It is very important to assess the life threatening factors in a seizure-affected child, especially to determine if the seizure affects respiration or not. Because all attempts to be applied to the child will depend on condition of impressibility of the child's respiration [13]. The information about monitoring seizures, importance of regular use of medications, what to do when coming to the control and the effects of disruption of the medication schedule should be given by well educated nurses.

Patients with epilepsy are reported to have problems, especially with respect to their drug treatment and psychosocial lives. It is stated that the majority of patients with active epilepsy in developed countries do not regularly take antiepileptic drugs (AEDs). It is stated that the most important reason for this is the lack of specialized health work in epilepsy management. The World Health Organization (WHO) has recommended to use of primary health care workers for identifying the causes of epilepsy, to apply appropriate treatment protocols and to monitor treatment within the framework of integrated health care protocols in order to resolve these problems [14]. In many countries, "epilepsy nurses" are interested in children with epilepsy. In our country, "pediatric epilepsy nurses" are needed for epileptic children. Epilepsy nurses can discuss important clinical issues with patients and their families and can make training more productive. Understanding of the information provided by children and families will reduce potential misunderstandings. At the same time, information is also important in terms of continuity and safety of care [15].

Nurses dealing with epilepsy plan about the needs of epileptic patients and their families by evaluating the knowledge levels of the epileptic children about the disease, the way they perceive the disease, and the factors affecting treatment compliance. For this purpose, it is necessary to cooperate with patients, parents and nurses, to solve the psychosocial problems of people with epilepsy and to increase the quality of life (table 1). In a study by Isler and., *et al*, inactive learning methods are reported to improve epileptic children and their families in the areas of knowledge, neuropsychological and quality of life. All health workers who are interested in epilepsy children regularly use these modular training programs [16].

Problems	Nursing approaches
What is epilepsy?	Explanation to the family about diagnosis, giving information, answering questions if any
Not accepting the diagnosis of epilepsy	To explain that epilepsy is not a fearful disease, there are treatment options.
How can I use the drugs?	To ensure that regular drug use is necessary and to learn its importance
What are the factors that stimulate the seizures?	Bright flashing lights, hunger, insomnia, alcohol intake are explained to stimulate seizures
What should they do in case of illness?	Epilepsy medicines should continue to be used in the same way, but they should show the doctor they use to avoid drug interaction.
What should I do if I have a seizure?	When there is a seizure, calm down, secure the patient, take time, hold time and call an ambulance if it does not stop within 3-5 minutes.
What should I do if there is a fever?	Measure the fever, open it up, give it the appropriate dose of antipyretic, follow the fever

Table 1: Problems encountered in children with epilepsy and nursing approaches.

The National Institute for Health and Clinical Excellence (NICE) 2004 and the Scottish Intercollegiate Guidelines Network (SIGN) 2005 guidelines had defined the need for child epilepsy nurses as ‘an integral part of the maintenance network’ [17,18]. NICE quality standards state that children and adolescents with epilepsy need to be looked after by epilepsy specialist nurses (2013). New publications have also shown that urgent action should be taken to ensure that this standard is met as soon as possible. Epilepsy Action (2013) reported that about half of the epilepsy services in the UK did not have epilepsy nurses and that 42% of the children who still have seizures did not see any epilepsy nurses. In about 30% of epileptic patients, the seizures are relatively resistant to medications. Even in the case of AED treatment doses used in patients, they may cause undesirable side effects. Some of the patients with drug resistant epilepsy may benefit from surgical interventions. However, in patients not eligible for epilepsy surgery, alternative methods of treatment include ketogenic diet (KD) and vagal nerve stimulation (VSS) [19].

Nursing approaches in ketogenic diet treatment

The ketogenic diet is a treatment that has been in use since 1920s. With the rapid introduction of the new AED into practice, KD treatment has lost its popularity however KD therapy has increasingly been used for the last 15 years [20]. Although the anticonvulsant effect is not fully known, it is thought that the effect of KD is mediated by possible antiinflammatory activity caused by increased ketone levels in the body [21,22]. It is believed that ketozsis causes a change between excitatory and inhibitory neurotransmitters [23]. On the other hand, KD may improve neuronal energy metabolism by affecting the mitochondrial system [24].

The generally accepted view is to add KD to current AED treatment. Original KD includes high fat and low carbohydrate diet [25,26]. The diet consists of high fat (90%), sufficient protein (1 gm/kg) and very little carbohydrate. The aim is to provide ketosis and ensure that oils are used as a primary energy source. Diet will be regulated in a way of providing development according to the child’s age, and ketosis will be regulated in a way of controlling the seizure. The level of ketone is frequently observed in the urine of the child.

Unresponsive epilepsies to two or three medications are defined as drug resistant epilepsy (DRE). Epilepsy surgery is the best treatment if there is an epileptic focus that can be removed in the DRE, but for children who do not have such a chance, the KD may be the best treatment option. KD can be effective for almost any type of seizures, including jeneralize, focal and mixed type seizures, and there is no statistical difference between seizure types and effectiveness [25]. For almost a century KD and similar diets have been used all over the world. At 50 - 60% of children who received this diet, a seizure reduction of more than 50% in about half of patients [24]. According

to current consensus, if there is no contraindication, KD should be considered early in the care of DREs, not as the last treatment option [27]. Contraindications such as disorders of fatty acid metabolism, and primary carnitine deficiency should be screened before starting the ketogenic diet, better results are obtained if KD is initiated early in some diseases such as Dravet syndrome, infantile spasm, myoclonic-atonic epilepsy (Doose syndrome) and tuberous sclerosis [25]. It is clear that for the success and safety of the KD, the best possible outcome is obtained by an experienced team of physicians, dietitians and nurses with close follow-up of the patient [28]. Seizure type and/or epilepsy syndrome should be determined before starting the KD. The comorbidities which may deteriorate with the initiation of KD including (kidney stone, dyslipidemia, liver disease, growth retardation, gastroesophageal reflux, poor oral intake, constipation, cardiomyopathy and chronic metabolic acidosis should be screened before starting the KD). The carbohydrate (KH) content of the AED that is being used should be taken into account and is replaced by a lower or KH-free form (e.g. tablet forms) if possible. The child's food preferences and personal characteristics, food intolerance, cultural or local habits should be learned before meals are planned. Discussion of the expectation of the family by making a separate training meeting by a team consisting of an educated dietician and nurses before starting the diet increases the success of the KD. Once the metabolic screening and laboratory tests indicate that there is no contraindication, the KD can be started without admission of the child to the hospital but with a close follow-up by an experienced KD team [24]. The expectation for each child must be determined in a realistic manner and should be indicated to the family to be monitored for a decision to continue treatment after a minimum of 3 months. the preparation of meals, management when child is ill (fever, diarrhea), ketone and sugar measurements should be taught to the parents and/or caregivers. Families should be aware of the acute and chronic complications that may occur during KD and should be given a form of approval before the start of treatment. A care plan should be made to ensure that glucose and products containing glucose must not be applied in urgent applications [29].

Side effects of the ketogenic diet include reflux, vomiting, constipation, diarrhea, abdominal pain, hypoglycemia, hyperlipidemia, dehydration, and loss of bone density. These adverse effects can be reduced or treated by close follow-up and dietary supplementation [25].

Establishing a good bond with the patient and the family increases the success of the ketogenic diet. It is necessary to adhere strictly to the recommendations and sometimes to add dietary supplement (vitamins, minerals) in order to keep the diet healthy. Regular laboratory screening are necessary to ensure that the diet can be applied for a long time. The patient and family should also monitor medicines and personal care products (such as toothpaste, sun cream, etc.) as they may alter the amount of carbohydrates they need daily and impair seizure control.

Other dietary treatment options such as Modified Atkins and the low glycemic index diet are also available for patients with DRE. These diets are less restrictive than KD and they can be practised more easily by adolescents. However, dietary supplements need to be monitored closely by the multidisciplinary KD team [30].

The ketogenic diet nurse communicates between the patient and team members, and provides patient training before and after the diet begins. Connecting with the patient and family increases KD success. For this, the family must follow the diet strictly and sometimes they need to add many diets to stay healthy. In order to make the diet for a long time, regular laboratory examinations (at 1, 3, 6, 12, 18 and 24 months) are required. KD nurses in the team arrange patient appointments, meet the patient, direct them to consultations, plan laboratory tests, and provide results to the doctor [12]. The role of the nurse is shown in table 2.

Patient selection
Provides the selection of the appropriate patient and directs the child to the neurologist
To give the family the necessary information about the ketogenic diet (for outpatient or inpatients).
Evaluates the readiness of the patient/family to the diet;
Willingness to -2-3 months trial period
Willingness to life type changes
Evaluates support systems
Determines behavior changes

Starting
The family's understanding of KD
Monitoring the patient's condition
Completing KD Education
Monitoring of seizure activity
Teaching the signs/symptoms of ketone elevation/hypoglycaemia
Disease management plan
Reducing side effects (constipation/diarrhea, kidney stones, etc.)
Teaching the family enteral nutrition
Describing emergency seizure management
- Information about emergency drugs
First aid to seizures
112 issues when to call the emergency/when to go to the emergency room

Tablo 2: Duties of the nurse in the ketogenic diet team.

Conclusion

It is very important for nurses to know the problems faced by patients with patients care-givers and to know how to cope with them [31]. For this purpose, it is necessary to establish good communication between patients, families and nurses in order to improve the quality of life and to solve psychosocial problems of children and families with epilepsy [32]. As in developed countries, the development of pediatric epilepsy nursing, which deals with childhood epilepsy, is essential to solve such problems.

Bibliography

1. Yeni SN. "Epilepsi epidemiyolojisi". *Turkiye Klinikleri Jounal Neurol-Special Topics* 1.2 (2008): 9-16.
2. Banerjee PN., et al. "The descriptive epidemiology of epilepsy". *Epilepsy Research* 85 (2009): 31-45.
3. Uysal S and Ercan T. "Epilepsi, spor, psikososyal yaşam". *Türk Pediatri Arşivi* 40 (2005): 68-71.
4. Rodgers CC. "The child with cerebral dysfunction". In MJ Hockenberry, D Wilson (Edition.), Wong's Nursing Care of Infants and Children, 10th Edition. Elsevier Mosby, Canada (2015): 1470.
5. Shore C., et al. "Psychosocial care needs of parents of children with new onset seizure". *Journal of Neuroscience Nursing* 30 (1998): 169-174.
6. Mc Nelis AM., et al. "Concerns and needs of children with epilepsy and their parents". *Clinical Nurse Specialist* 21 (2007): 195-202.
7. Shaju M., et al. "Knowledge, attitude and practice of parents regarding pediatric antiepileptic drug therapy". *International Journal of Epilepsy* 1 (2014): 57-63.
8. Hung Anchor TF. "Psycho-social impact of epilepsy and issues of stigma". *Medical Bulletin* 14 (2009): 15-17.
9. Hills MD. "The psychological and social impact of epilepsy". *Neurology Asia* 12.1 (2007): 10-12.
10. Hung Anchor TF. "Psycho-social impact of epilepsy and issues of stigma". *Medical Bulletin* 14 (2009): 15-17.

11. Thacker AK, et al. "Knowledge awareness and attitude about epilepsy among schoolteachers in India". *Seizure* 17 (2008): 684-690.
12. Smith Gigi, et al. "Epilepsy Update, Part 2 Nursing Care and Evidence-Based Treatment". *AJN The American Journal of Nursing* 6 (2015): 34-44.
13. Ayşegül İşler, et al. "Modüler Eğitim Modeli ile Epileptik Nöbeti Olan Çocuğa Yaklaşım". *Türkiye Klinikleri Journal of Neurology* 6.2 (2011): 39-46.
14. Adamolekun B, et al. "An evaluation of the management of epilepsy by primary health care nurses in Chitungwiza". *Zimbabwe Journal of Epilepsy* 10 (1997): 294-297.
15. Scambler A, et al. "Towards an evaluation of the effectiveness of an epilepsy nurse in primary care". *Seizure* 5.4 (1996): 255-258.
16. Turan Gürhopur FD and İşler Dalgıç A. "The effect of a modular education program for children with epilepsy and their parents on disease management". *Epilepsy and Behavior* (2017): 30430-30434.
17. Dunkley C and Cross JH. "NICE guidelines and the epilepsies: how should practice change?" *Archives of Disease in Childhood* 91.6 (2006): 525-528.
18. Planjar-Prvan M and Granić D. "[Guidelines for management of epilepsy--commentary on Scottish ("SIGN") guidelines]". *Acta Medica Croatica* 59.1 (2005): 75-77.
19. National Institute for Health and Clinical Excellence. "The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care (update)". *Clinical Guideline* 137 (2012).
20. Cross JH and Neal EG. "The ketogenic diet--update on recent clinical trials". *Epilepsia* 49.8 (2008): 6-10.
21. Jeong EA, et al. "Ketogenic diet-induced peroxisome proliferator-activated receptor- γ activation decreases neuroinflammation in the mouse hippocampus after kainic acid-induced seizures". *Experimental Neurology* 232.2 (2011): 195-202.
22. Wilder RM. "The effects of ketonemia on the course of epilepsy". *Mayo Clinic Proceedings* 2 (1921): 307-308.
23. Hartman AL, et al. "The neuropharmacology of the ketogenic diet". *Pediatric Neurology* 36.5 (2007): 281-292.
24. Kossoff EH and Wang HS. "Dietary therapies for epilepsy". *Biomedical Journal* 36.1 (2013): 2-8.
25. Kossoff EH, et al. "Optimal clinical management of children receiving the ketogenic diet: recommendations of the International Ketogenic Diet Study Group". *Epilepsia* 50.2 (2009): 304-317.
26. Klepper J, et al. "The ketogenic diet in German-speaking countries: update" (2003).
27. Wang HS and Lin KL. "Ketogenic diet: an early option for epilepsy treatment, instead of a last choice only". *Biomedical Journal* 36.1 (2013): 16-17.
28. John M Freeman and Eric H Kossoff Adam L. "Hartman The Ketogenic Diet: One Decade Later". *Pediatrics* (2007): 3.
29. Ünalp A. "Ketogenic diet practices in childhood epilepsies" *İzmir Dr. Behçet Uz Çocuk Hast Dergisi* 7.3 (2017): 169-177.
30. Kossoff EH. "International consensus statement on clinical implementation of the ketogenic diet: agreement, flexibility, and controversy". *Epilepsia* 49.8 (2008):11-13.
31. Oto R, et al. "Epilepsinin psikososyal etkileri". *Klinik Psikiyatri Dergisi* 7 (2004): 210-214.
32. Bek S, et al. "Epilepsi tedavisinde klasik ve yeni antiepileptik ilaç seçimi". *Türk Nöroloji Dergisi* 15 (2009): 71-77.

Volume 9 Issue 8 August

2020© All rights reserved by Aycan Ünalp, et al.