

**USING THE KETOGENIC DIET TO REDUCE THE
INCIDENCE OF PEDIATRIC SEIZURES: HELPING
CHILDREN AND FAMILIES TO FIND A BETTER
QUALITY OF LIFE**

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By

Alison Wohler

Dr. Nancy Ebersole
Faculty Advisor
School of Nursing

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Abstract

Seizure disorders have both medical as well as quality of life implications for anyone experiencing them. The use of medications to control and manage this disorder is not always effective and may cause side effects that discourage compliance with the prescribed drugs. All of these concerns are especially problematic for children with seizures and their families. The use of diet modifications to control seizures is showing promise as an alternative to medications. The high fat, ketogenic diet as well as the low glycemic index diet are being investigated to control seizures in children. A systematic review of the literature was done in the CINAHL Plus database. The themes identified across the studies are (a) the ketogenic diet was effective in reducing seizures whereas the low glycemic index diet was not; (b) compliance with diet changes is a significant concern in this patient population; (c) parents view quality of life differently than the children with seizure disorders and this can impact diet adherence; and (d) how this diet interacts with medications and alters other body functions must be considered when using the ketogenic diet for seizure management. These results indicate an opportunity for nurses to work with families and the health care team to reduce the incidence of seizures, improve treatment compliance, and enhance the quality of life. A treatment option which provides for the needs and desires of both the individual and the parents can strengthen the family unit and promote healthy outcomes for all.

Key words: Pediatric seizures, diet, ketogenic diet.

Table of Contents

Abstract	i
Acknowledgements	iii
Introduction	1
Background	1
Methods	4
Results	5
The Ketogenic Diet Was Effective in Reducing Seizures, Whereas the Low Glycemic Index Was Not:	6
Parents View Quality of Life Differently Than the Children with Seizure Disorders and This Can Impact Diet Adherence:	7
Compliance with Diet Changes is a Significant Concern in this Patient Population.	8
How This Diet Interacts with Medications and Alters Other Body Functions Must Be Considered When Using the Ketogenic Diet for Seizure Management.	9
Discussion	11
Limitations	12
Conclusions	12
References	13

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Using the Ketogenic Diet to Reduce the Incidence of Pediatric Seizures: Helping Children and Families to Find a Better Quality of Life

According to the National Epilepsy Foundation, there are approximately 3.4 million Americans living with epilepsy (Osborne Shafer & Serven, 2013). Epilepsy is defined as a seizure disorder, that is diagnosed after a person has had at least two seizures, that are not caused by a known medical condition (Osborne Shafer & Serven, 2013). Seizures occur when there are several neurons in the brain that fire unexpectedly. There are several types of seizures, which affect different parts of the brain, and may present with different symptoms. Seizures can affect all age groups; however pediatric seizures can be more difficult to control.

The National Epilepsy Foundation estimates that about 470,000 American children have epilepsy (Osborne Shafer & Serven, 2013). Patients are usually treated with high doses of seizure medications, which are required to treat difficult to diagnose seizures. Despite the use of medications, seizures still persist. Children and their families struggle with seizure disorders because safety is a huge concern, with seizure related injuries. During a seizure, the individual does not have control of his or her body. Thrashing, shaking, twitching, and falls are events that may occur during a seizure. It can be very frightening for the family during a seizure, and they can feel helpless. For those who do not respond well to conventional treatment, consideration of alternative effective therapies may need to be considered.

Background

Causes of pediatric epilepsy are categorized into five groups: genetic, structural, metabolic, immune related, or infection (Wirrell & Sheildley, 2020). There are several

types of genetic conditions that cause epilepsy in children. Some disorders are inherited, meaning they are passed down from their parents on a chromosome (Wirrell & Sheildley, 2020). Structural epilepsy can be due to a trauma to the brain. Metabolic epilepsy may occur if the body's normal breakdown of nutrients into energy is incomplete or disrupted, therefore disrupting the brain cells functioning due to inadequate nutrition. Immune related epilepsy occurs when the child has an abnormal antibody that builds up in the blood or cerebrospinal fluid, causing brain inflammation (Wirrell & Sheildley, 2020).

Certain seizures can also result from infections or illness. Febrile seizures are seizures that may develop as the result of having a high fever. This specific type of seizure usually goes away with the reduction of the fever. Status epilepticus is a type of seizure that lasts longer than five minutes, or clusters together one after another. Acute seizures can occur as a result of disease, trauma, or infection, that can be treated. Chronic seizures can also be referred to as epilepsy, which is lifelong. While each seizure type may have a different cause, the seizure itself results from the same interruption in brain activity (Wirrell & Sheildley, 2020).

Determining the seizure type is integral for treatment. Diagnosing a child with epilepsy is first achieved by obtaining a detailed medical history. Next, an electroencephalogram (EEG) is performed to monitor electrical activity and track the seizure activity occurring inside the brain. An MRI or CT scan may be done to look for structural abnormalities as well. According to The Epilepsy Foundation, the goals for treatment should consist of “no seizures, no side effects” (Schachter, Osborne Shafer, & Serven, 2013). Treatment options for patients consist of surgery to correct structural

causes, neurostimulation devices to correct electrical impulses, clinical trials to try experimental therapies, and medications (Schachter, et al., 2013).

Seizures present issues for families, including difficulties with treatment regimens, balancing the families' needs, and promoting the child's growth and development. Families who have a child with a chronic seizure disorder often have difficulties with the demands of adhering to a treatment regimen, such as the cost of medications, transportation to appointments, and hospital costs. Balancing the needs of their other children and household can also put a strain on parents with a chronically ill child. Promoting the child's growth and development is also difficult, as the seizures can cause damage to brain cells causing disruptions in cognitive functions. Some children can suffer from intellectual and physical disabilities due to their seizures, as well as sleep disturbances (Schachter, et al., 2013).

Changing a child's diet can be difficult, but it has shown promise for optimal seizure control. The ketogenic diet is a nutritional plan where patients consume high amounts of fat, and low amounts of carbohydrates, with adequate protein intake (Amari, Turner, Rubenstein, Miller, Kossoff, 2015). The body usually metabolizes carbohydrates for energy, and when there are no more, it uses fat for energy. Fat metabolism produces ketones, which are chemicals created by your liver when your body has a low supply of carbohydrates. When the body uses fat as an energy source, it has anti-inflammatory effects, as well as anti-epileptic action (Lin, Lin, Chan, Hsia, Wang, 2015). The dietary changes can alter the action of neurotransmitters in the brain, which can cause seizure activity to lessen or stop completely. According to Amari et al., children who experience seizures have been shown to have a preference for foods with a higher fat content, which

makes the diet a viable option, as it lines up with food preference in pediatric patients (2015).

Quality of life on this diet is not always optimal. Children struggle with food choices being limited and families struggle to prepare the foods. Patients also deal with feeling socially isolated, as children on the ketogenic diet cannot have foods high in carbohydrates, such as pizza and cake at a birthday party. They may feel different from their peers, as they have to eat different foods, and cannot share lunches or snacks with their friends. According to Boles et al., a loss of independence, needing help preparing foods, and getting medications is a problem with older, adolescent children, as they want to do everything themselves (2020). It is often hard to get adolescents and young adults to comply with the diet, as parents have less control of what they eat. As children get older, they are more self-sufficient and are out of the house more with friends. This creates a compliance issue, which affects the efficacy of the diet (Boles et. al, 2020). The aim of this literature review is to describe the efficacy of the ketogenic diet, and whether it should be considered in children with drug resistant seizures.

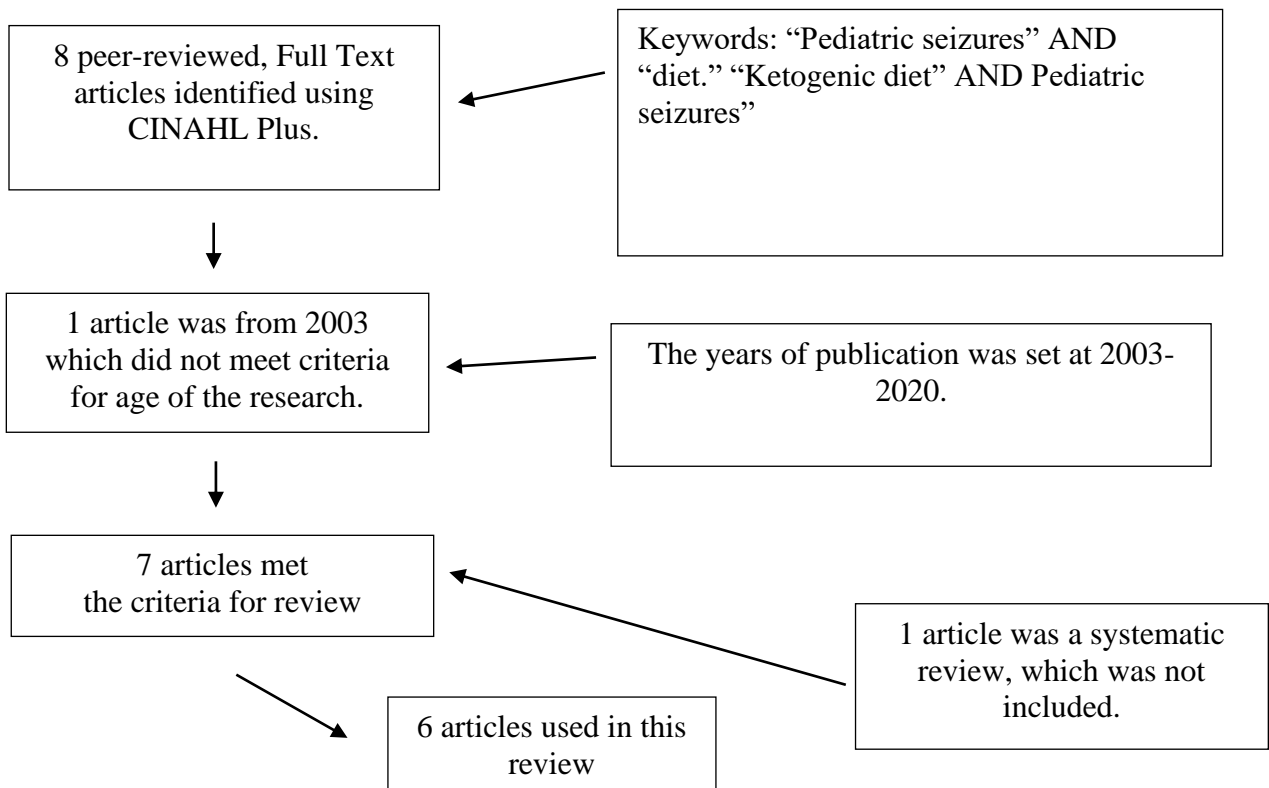
Methods

This systematic review of the literature was done to identify the effectiveness of the ketogenic diet in controlling seizure disorders. The articles chosen had to include pediatric patients specifically, who have epilepsy, and were on the ketogenic diet.

The database Cumulative Index of Nursing and Allied Health Literature (CINAHL) Plus with Full Text was used. A Boolean search was conducted using the key words pediatric seizures, diet, and ketogenic diet. My first search did not have date parameters, so one article was omitted as it was eighteen years old. The search was

narrowed down to the years of 2014-2020 as I was looking for the most recent evidence of this diet's effectiveness. See Figure one.

Figure 1 Journal Article Identification: Pediatric Seizure Control with the use of the Ketogenic Diet



Results

Six articles met the criteria for showing the importance of diet in seizure control. Within the six articles, four major themes were identified; (a) the ketogenic diet was effective in reducing seizures whereas the low glycemic index diet was not; (b) parents view quality of life differently than the children with seizure disorders and this can impact diet adherence; (c) compliance with diet changes is a significant concern in this

patient population and (d) how this diet interacts with medications and alters other body functions must be considered when using the ketogenic diet for seizure management.

The Ketogenic Diet Was Effective in Reducing Seizures, Whereas the Low Glycemic Index Was Not

For patients receiving the ketogenic diet, there was a reduction of seizures in different groups of pediatric patients (Janak et al., 2019; Le Pichon et al., 2019; Lin et al., 2015; O’Conner et al., 2014). Janak et al. reports as much as a 50% reduction in seizure activity for some patients, while 10-20% of patients actually became seizure free (2019). For some infants, use of medications to control seizures was no longer needed (Le Pichon et al., 2019; Lin et al., 2015). For patients with the life-threatening condition of status epilepticus, the ketogenic diet was effective in reducing this type of seizure activity (O’Conner et al., 2014).

What kind of diet a seizure patient is started on can have different effects on seizure control. The low glycemic index diet is less restrictive in nature, but it does not contain the same types and amounts of fat used. The low glycemic index diet was not effective in reducing seizures (Boles et al., 2020). According to Boles et al., the low glycemic index diet allows for 10-15% of carbohydrates, while the ketogenic diet allows for a strict 4% (2020). The difference in carbohydrate amount is significant, as a liberal intake of carbohydrates is not as effective for optimal seizure control (Boles et al., 2020).

According to Janak et al., on the usual polyunsaturated fat ketogenic diet, fifty percent of patients report a greater than fifty percent reduction in seizure activity, and ten to twenty percent become seizure free (2019). Upon switching to a mixed fat, ketogenic diet, eighty-eight percent of patients reported a greater than fifty percent reduction in

seizure activity, and sixteen percent of patients were seizure free (Janak et al., 2019). O’Conner et al. reports that the ketogenic diet is usually used for generalized epilepsy, but in her case study the diet was successful for patients with various EEG patterns, with both general and focal seizures (2014). Lin et al. found that early initiation of the ketogenic diet was beneficial, as most patients responded to the diet in seven to ten days (2015).

Parents View Quality of Life Differently Than the Children with Seizure Disorders and This Can Impact Diet Adherence

The results of the ketogenic diet are shown to impact the quality of life for both the child and the family. Parents report that the reduction in seizure activity has had a positive impact on life in the home (Boles et al., 2020; Le Pichon et al., 2019). Parents find that this allows them to work with the child in selecting foods and trying new recipes (Boles et al., 2020) while others are pleased that the diet can be given intravenously if needed with the same result of fewer seizures (Lin et al., 2015). Children however say that being on a restricted diet means more restrictions in their life resulting in them feeling isolated as they do not get the choices that their peers do (Boles et al., 2020).

The quality of life on the ketogenic diet is what is the most debated aspect of the diet itself. While the effects of the diet are quite desirable, it can have an effect on the child’s mental health. There is a feeling of isolation and loneliness due to eating foods that are different from their peers. Boles et al. collected data using the Pediatric Quality of Life Inventory Questionnaire, which measures quality of life for patients between the age of two to eighteen (2020). Children on the ketogenic diet reported having a low quality of life contrary to their parents who reported various degrees in quality-of-life

changes. Children reported missing comfort foods, while parents were excited to try new recipes (Boles et al., 2020). According to Boles et al., adolescents on the diet reported a decrease in quality of life by 7.3% (2020). The key difference is that the parents see quality of life as seizure free, while the children only see the diet restrictions and isolation.

There are however positive implications of the diet on a child's quality of life. Parents and children can spend more time together planning out meals and grocery shopping together, and the whole family can be involved in meal preparations. Children and families together will try new foods, become more health conscious, make smarter lifestyle choices, and spend more time together (Boles et al., 2020). These moments of family bonding can also help the child feel important and that their seizure disorder is taken seriously. The diet can also be offered intravenously in the hospital so patients can still get the nourishments they need (Lin et al., 2015). Mothers are also able to breastfeed their infants on the ketogenic diet, which strengthens mother-child bonding (Le Pichon, Thompson, Gustafson, Abdelmoity, 2019).

Compliance with Diet Changes is a Significant Concern in this Patient Population

Dietary compliance is a major factor in effectively reducing seizures (Amari et al., 2015; Boles et al., 2020; O'Conner et al., 2014). Eating has both social as well as physiological effects on overall health. Food preferences change as children pass through different phases of growth and development, which can make compliance with this diet difficult (Boles et al., 2020). The differences in this diet from what peers are eating will change as the child grows (Amari et al., 2015), and the need to be a part of a social group may result in low dietary compliance (Boles et al. 2020). It is important to look at which

fat choices produce good seizure control, and which do not (Amari et al., 2015). Not being able to eat high-carb, comfort foods on the ketogenic diet can be quite difficult especially for children. Their food preferences are always changing, and some are very picky eaters. Even though the ketogenic diet works in controlling seizures in patients as young as infants, there is very low adherence to the diet itself (Boles et al., 2020).

The diet can also be given enterally through a feeding tube, or intravenously, as well as an addition to breastfeeding which makes it a viable option due to some seizure patients not being able to eat by mouth. According to O’Conner et al., providing the diet enterally enhances adherence, as well as safety, because it can be provided in formula, at a constant, set rate (2014). Mothers of infants are often concerned they will not be able to breastfeed, but according to Le Pichon et al., mothers can still breastfeed on the ketogenic diet by adding their expressed breast milk to ketocal, which is an approved ketogenic diet formula (2019). When mothers feel like they can still be a part of their infants feeding regimen, they are much more likely to comply.

Loss of ketosis, and ultimately loss of seizure control can occur if patients do not adhere to the diet. It is important for patients to be followed closely by a nutritionist, neurologist, and an intensive care team (O’Conner et al., 2014). Nurses play a key role in monitoring compliance and implementing early interventions to ensure ketosis is maintained.

How This Diet Interacts with Medications and Alters Other Body Functions Must Be Considered When Using the Ketogenic Diet for Seizure Management

For all of the positive effects seen with using the ketogenic to reduce the incidence of seizures, like all medical treatments there is a risk of creating new problems.

It is still not known which types of fats have the best effect, or how much is enough without being too much (Amari et al., 2015; Janak et al., 2019). The components of this diet rely heavily on the liver to be metabolized (Lin et al., 2015; O’Conner et al., 2014). The liver aids in metabolism by breaking down substances so they can be excreted from the body. In young children, the ketogenic diet can result in liver impairment and the possibility of long-term liver damage (Lin et al., 2015). Additionally, to achieve ketosis which is the environment created by this diet to reduce seizure activity, the number of carbohydrates administered with medications can make ketosis difficult to achieve (O’Conner et al., 2014). Carbohydrates affect the process of ketosis, because ketosis relies on fats, while normal metabolism uses carbohydrates. Too many carbohydrates will affect the efficacy of ketosis.

Medication use may need to be reevaluated while on the ketogenic diet, as many contain carbohydrates, and the ketogenic diet is a low carbohydrate diet. O’Conner et al. reports that providers must contact the pharmacy to get medications converted into carbohydrate free forms, so as not to add extra carbohydrates into a patient’s system (2014). Also, O’Conner et al. states that “if a patient is taking valproate or has high triglyceride levels, they will need to be on carnitine supplements” (2014). Valproate is a common anti-seizure medication and carnitine helps burn fat, which is affected by some anti-epileptics, such as valproate (O’Conner et al., 2014). A high triglyceride level or hypertriglyceridemia indicates that the body has an elevated level of fat in the bloodstream; this can occur on the ketogenic diet, as the body is breaking down fats for energy.

While on the ketogenic diet, there are several elements that need to be monitored. According to O'Conner et al., serum titers of metabolic labs such as your serum glucose level, electrolytes, kidney function, and liver function tests; tracking weight losses and gains, must be closely monitored to maximize ketosis as well (2014). It is also important to monitor for metabolic acidosis, as it can happen fast (O'Conner et al., 2014). Side effects that are most common include, nausea, vomiting, diarrhea, constipation, and lethargy which can be unpleasant for children (Janak et al., 2019). Dehydration is also a common side effect that children of all ages can experience (Le Pichon et al., 2019). Stress hyperglycemia is also an often-unrecognizable occurrence at the beginning of the diet which can make it very hard to achieve ketosis (Lin et al., 2015). Severe, but rare side effects that can also occur are pancreatitis, cardiomyopathy, and liver failure (Lin et al., 2015).

Discussion

This literature review shows that the ketogenic diet is promising for seizure control in pediatric patients. However, it comes down to how the diet makes the patients feel, and if they see it as effective for the seizure control. A seizure reduction can be achieved, but this isn't viewed in the same way by the child and the family. There is an issue between finding a balance between seizure control and dietary compliance, so that quality of life improves for everyone involved. Although the evidence points to good seizure control, this comes at the cost of having to look at its effects on the child's body. Parents have to decide if risking liver damage, and several gastrointestinal symptoms for seizure control is the best choice for their family.

Limitations

The database used to gather articles - CINAHL Plus with Full Text provided a low number of research articles that addressed this particular diet and the impact on the child and family. More databases could provide additional information. More studies with larger sample sizes would provide additional evidence as to the effectiveness and the safety of the ketogenic diet. Also, the six articles focused on different age ranges within the pediatric patient, so to have a definitive answer would require a much narrower age range.

Conclusion

The ketogenic diet has been shown to be effective for seizure control in pediatric patients, with the right balance of types of fats, and good dietary compliance. However, the diet is not for everyone as the side effects can be undesirable for patients, and cause parents to make difficult choices between being seizure free and increasing the risk of other medical conditions. The ketogenic diet does have positive implications that can bring families closer together and make treatment family oriented. Maintaining a positive quality of life is very important on this diet, as it can be greatly affected in vulnerable, school aged patients. This diet has been shown to work well in patients with seizure disorders and has helped get children off high doses of anti-epileptic medications that often do more harm than good. As nurses, this evidence can be used to inform practice and improve compliance, with the knowledge of the diet's success in improving seizure control. Additionally, nurses can aid families in understanding the risks of the diet and help them in making decisions that are in the best interest of both the child and the family.

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