Pediatric Intensive Care Nursing

Journal of the International Pediatric Intensive Care Nursing Association

In this Issue

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Editorial

Innovations in nursing practice

Our feature article in this issue of Pediatric Intensive Care Nursing discusses the ketogenic dietary therapy for refractory epilepsy. This article was submitted to PICN by Dr. José Palacio and colleagues.
This highlights a non-pharmacological strategy for diminishing seizures in this population, which entails numerous meticulous nursing interventions that are eventually managed by families in most cases.
Although this population frequently requires pediatric intensive care for stabilization, this therapy is managed throughout the illness continuum, from pediatric intensive care, to acute care, to living at home in the community – accompanied by skillful nursing support throughout.

We commend our authors for sharing this rich contribution with PICN.

It would be interesting to hear about additional innovations implemented in other settings. What kinds of innovations or practice changes are you working on in your unit at this time? What challenges and benefits are you experiencing? Consider publishing your work with us so our international readership can learn from your experience.

Thank you to Dr. Palacio and colleagues for sharing their valuable work and opening up this important discussion with our readership!

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Guidelines for Nursing Care of the Child on Ketogenic Dietary Therapy for refractory Epilepsy

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Key words: Ketogenic diet, nursing recommendations, refractory epilepsy, pediatric intensive care unit

Abstract

The purpose of this paper is to provide nursing recommendations for the care of the critically ill child on ketogenic dietary therapy. The ketogenic diet (KD) is a useful treatment for pediatric and adult patients with refractory epilepsy. Our recommendations aim to unify nursing criteria for the care of children and adolescents with refractory epilepsy on the KD. For the child with neurological and nutritional disorders, the role of the nurse in the interdisciplinary team is key in providing educational tools and strengthening the communication with the family. The goal is to achieve compliance to treatment. It would be necessary to develop an adequate nursing protocol to provide enhanced safety practices in the care of children on the KD.

Purpose

The purpose of this paper is to provide nursing recommendations for the care of the critically ill child on ketogenic dietary therapy.

Introduction

Epilepsy is a chronic disease that affects 0.5-1% of the population. Sixty percent of cases occur in childhood. Twenty to thirty percent of patients have refractory seizures and receive conventional treatment with antiepileptic drugs (AEDs). Status epilepticus (SE) is the most severe form of epilepsy. It is one of the most common neurologic emergencies, with an incidence of up to 61 per 100,000 per year and an estimated mortality of 20 % (Trinka 2015). Caring for these children is a therapeutic challenge for the entire healthcare team.
The ketogenic diet (KD) is a non-pharmacologic and effective treatment that has been used as alternative method for managing refractory epilepsy since 1992. (Caraballo R and Vining E. 2012; Neal et al, 2008) Several authors have made recommendations for selecting foods that are high in fat and low in carbohydrates while providing proteins that are appropriate for the child's age.

Guidelines for Nursing Care of the Child on Ketogenic Dietary Therapy for refractory Epilepsy

The amount of fat is three to five times greater than the sum of carbohydrates and proteins.

It is a mathematically calculated, individually controlled, medically rigid diet (Panico L, 1997). The classic KD is the one most often used in Argentina and at our center following the protocol of Johns Hopkins Hospital (Freeman et al, 1998) without fasting. Nursing interventions both in clinical practice and in educational areas are useful for the child with refractory epilepsy on the KD, improving implementation and adherence of the children to this therapeutic option.

An increased caseload of children with the diagnosis of refractory epilepsy put on the KD as a nonpharmacological treatment of the underlying disease has been observed in recent years in the areas of pediatric intermediate and intensive care, leading to a debate about the appropriate nursing interventions for the care of these children. Current scientific literature on this topic is lacking. Members of the Neurology and Nutrition Departments of the Pediatric Hospital Garrahan together with the Child Neurology Society of Argentina participated in the National Consensus on the Ketogenic Diet (Armeno M et al, 2014), (Hartman & Vining. 2017) .

They outlined some recommendations for nursing interventions for the child/adolescent with refractory epilepsy on the KD.

There are certain epilepsy syndromes in which the KD has proven to be effective in controlling seizures (Table 1).

Table 1: Frequent indications for ketogenic diet treatment
(*Source: National Consensus on Ketogenic Diet 2015)*

Glucose transporter type 1 (Glut1) deficiency syndrome
Pyruvate dehydrogenase deficiency
Severe myoclonic epilepsy (Dravet syndrome) and Epilepsie with myoclonic-atonic seizures (Doose syndrome)
Lennox-Gastaut syndrome
Epilectic encephalopathy with continuous spike-waves during slow sleep
Landau-Kleffner syndrome
Fever induced refractory epileptic encephalopathy of school-age children
Other (infantile spasms, structural and focal epilepsies of unknown cause)

Nursing recommendations

Recent reports have promoted the use of the ketogenic diet as an effective treatment for refractory status epilepticus. There are no consensus guidelines on standard care for SRSE, but here we describe our approach to initiation of KD in the pediatric intensive care unit.

Guidelines for Nursing Care of the Child on Ketogenic Dietary Therapy for refractory Epilepsy

- For the diet to be successful, it is essential to achieve treatment compliance through education and communication with the child/adolescent during the active disease process.
- It is necessary to emphasize the role of nursing educators in the metabolic unit for parents regarding the control of ketones in urine during hospitalization and monitoring after discharge on an outpatient basis.
- The focus of treatment is on feeding management. If the child does not have swallowing difficulties, the diet can administered orally. In children with swallowing problems, the diet can administered using a commercial formula with a ketogenic ratio of 4:1 (4 grams of fat for every 1 gram of protein plus carbohydrate). In these cases the diet is administered through continuous infusion via a nasogastric tube or gavage pump.
- The nasogastric tube should be washed after each administration as the formula may cause occlusions due to its high fat content.
- During the start-up phase, the ketogenic ratio is increased on four consecutive days to achieve an adequate range for ketosis. Acute adverse effects that may occur during diet initiation are: hypoglycemia, metabolic acidosis, nausea, vomiting, and diarrhea. The nurse should be alert to clinical changes.
- An important role of the nurse is to control strict adherence during the stage of ketosis induction, since ketosis as well as glucose threshold parameters are searched for.
- Ketonemia may occur as a result of the KD and can produce hypoglycemia. Therefore, glucose levels should be assessed once per shift by monitoring capillary blood glucose test strips, indicating 24-hour blood sugar levels of the child.
- The values found on the nursing sheet should be assessed by the healthcare team. A blood glucose value at or below 65 mg is considered as hypoglycemia. The nurse should also recognize signs and symptoms of hypoglycemia, including: nervousness or anxiety, chills, sweating, irritability, confusion, rapid heartbeat, dizziness, tremors, and loss of consciousness. If hypoglycemia is suspected, the physician should be notified.
- The presence of ketones in urine should be assessed once each shift by using test strips used for that purpose, documenting the findings and communicating any changes to the attending physician. The aim of the KD is that the patient reaches CC ++ ketonuria with values of 80 mg/dl (Armeno M et al, 2014, Hartman and Vining, 2017) and glycosuria should be negative.
- A recent recommendation is to monitor the blood ketone dipstick. Measurement equipment should be available (e.g., Optium Free style, Abbot) and test strips should be used in a uniform fashion according to the indications of the nutrologist. The desired range in these patients is 2-6 mmol / l (Caraballo R, 2017).
- Vital signs should be monitored every two hours: Heart rate, blood pressure, temperature, respiratory rate, oxygen saturation. If children are hospitalized in intermediate care, the patient should be monitored twice per shift.

Guidelines for Nursing Care of the Child on Ketogenic Dietary Therapy for refractory Epilepsy

- Intake and output should be controlled once per shift and documented on the balance sheet every 24 hours to evaluate tolerance of the KD, as these children may develop metabolic acidosis, gastrointestinal symptoms (nausea, abdominal pain, and food intolerance with the risk of dehydration) during the initiation phase of the KD.
  A nursing flow sheet should be used to record seizures.
- The child should be weighed once a week to assess the metabolic nutritional status and results should be recorded on the nursing sheet for nutritional assessment.
- The hospital pharmacy should be notified when a patient is started on a KD. The pharmacy should modify the medications containing carbohydrates that the patient is receiving.
- Glucose syrup administration should be avoided as it increases carbohydrates which should be restricted when on the KD.
- If tablets are administered orally or by nasogastric tube depending on the presence or absence of swallowing difficulties, the medication should be diluted in distilled water.
- If the patient receives parenteral solutions (sedation, parenteral fluids, inotropics etc.), solutions should be prepared in saline (not dextrose).
- If the patient is receiving oral food, the diet should be administered according to medical indications with vitamins and mineral supplements because of the low variability of macronutrients in the KD. It is recommended to educate the patient and family about the benefits of sun exposure for the incorporation of vitamin D.
- Due to prolonged use of AEDs, calcium should be administered as medically indicated to prevent osteopenia and osteoporosis.
- AEDs are administered according to the neurology protocol for each patient individually.

Conclusions

The KD diet is a useful treatment for pediatric and adult patients with refractory epilepsy.
Our recommendations aim to unify nursing criteria for the care of children and adolescents with refractory epilepsy on the KD. For the child with neurological and nutritional disorders, the role of the nurse in the interdisciplinary team is key in providing educational tools and strengthening the communication with the family.
The goal is to achieve compliance to treatment. It would be necessary to develop an adequate nursing protocol to provide enhanced safety practices in the care of children on the KD.

Guidelines for Nursing Care of the Child on Ketogenic Dietary Therapy for refractory Epilepsy

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Multicultural Care in European Intensive Care Units - an Erasmus+ Project

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First Announcement

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Pediatric Intensive Care Nursing

Pediatric Intensive Care Nursing is indexed in CINAHL: Cumulative Index to Nursing and Allied Health Literature. **ISSN 1819-7566**

This Journal is a publication of the International Pediatric Intensive Care Nursing Association (for more information, join our egroup: http://groups.yahoo.com/group/PICU-Nurse-International).
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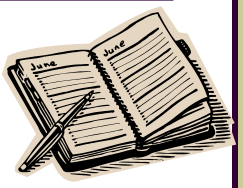

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Manuscripts must be written in English; either American or British spelling may be used but must be consistent throughout. Manuscripts should be typed double-spaced, using Arial or Times New Roman font in at least 11-point, with margins of at least 2 cm or 1 inch. Number pages consecutively beginning with the title page. The preferred length for research, clinical and review papers is 1000-2500 words, excluding references. Submissions to Spotlight on PICU should not exceed 1500 words. The sections of the manuscript should be in the following order.

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- Title should be concise and informative, and typed in bold capitals.
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- Include a maximum of 4 qualifications for each author
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Abstract

An abstract not exceeding 250 words is required for all submissions except those for Spotlight on PICU. For research studies, the abstract should be structured under the following headings: Background, Methodology, Results (or Findings), Conclusions.

Body of text

Use headings to structure the paper. The type of paper will determine the headings, e.g. for research papers the main headings will be Introduction, Background, Methodology/Methods, Results/Findings, Discussion, Conclusion. Up to 2 levels of headings may be used. Papers reporting research conducted in humans or animals should include a statement that the study was approved by the relevant body or bodies.

References

The list of references should only include works that are cited in the text and that have been published or accepted for publication. References such as "personal communications" or "unpublished data" cannot be included in the reference list, but can be mentioned in the text in parentheses.