Best Nursing Interventions for Educating Parents on Tyrosinemia Type I

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Overview

Tyrosinemia Type I (TTI) is a rare disease called an autosomal recessive inborn error of metabolism. The disease has a poor prognosis if not diagnosed early. The CDC estimates that 5-6% of deaths labeled Sudden Infant Death Syndrome (SIDS) are attributed to metabolic errors. TTI varies in its degree of symptoms, and not all states use the most reliable screening measure during the heel stick. Educating parents on the pathophysiology, symptoms, screening process, genetic counseling, and current research is key to getting more children diagnosed at an earlier stage to improve prognosis.

Methodology

A 2 step study is currently taking place.
1. Content expert review: Current researchers, nurse practitioners, pediatricians, pediatric nurses, and genetic counselors will be providing content expertise related to best practices in educating parents on TTI.
2. Parent focus group: A group of at least 4 parents will be given an educational pamphlet and watch a PowerPoint presentation to determine which material is more beneficial in educating about TTI.

Receiving feedback from experts and parents will provide the knowledge of how to best educate parents regarding TTI and diseases similar to it.

Impact

Educating the public will bring attention to the importance of newborn screening to decrease SIDS incidence and promote research to cure TTI, and other autosomal recessive diseases such as cystic fibrosis.

Explanation

Nurses are considered primary health educators by the public. Effective education can improve quality of life. Currently research is being conducted at UAH to help find a cure for TTI, and raising awareness to the public will further the cause.

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