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NUTRITIONAL EDUCATION FOR PARENTS OF A JORDANIAN CHILD WITH GLYCOGEN STORAGE DISEASE TYPE IIIa

Safa'a Al-Zeidaneen, Al-Balqa' Applied University, Jordan

¹Jordan University of Science and Technology, Irbid-Jordan

Background: Glycogen storage disease (GSD) type IIIa also known as Cori disease is a rare inborn error of metabolism characterized by a deficiency in glycogen disbranching enzymes. The medical nutritional therapy is the main management process.

Objective: To evaluate the parents knowledge about nutritional role in glycogen storage disease type IIIa of.

Methods: In this study the parents of a 2 year-old Jordanian male who is known to have a glycogen storage disease type IIIa (GSD IIIa), were interviewed and the extent of their knowledge about nutritional role in management of GSD IIIa were evaluated through valid and reliable questionnaire. The parents were asked about family history, their child breast feeding, doctor visit time, current child diet and what they want to know about the role of nutrition in their child case.

Results: The parents report that they were to follow the medical advice for managements of their child but they need to spend more time with health care professionals to understand the case and the managements of related complications as it is difficult to control all type of available foods especially for a 2 years old child within family containing 3 other children. However, the parents realize the importance of nutritional intervention and need for understanding the basic of nutritional therapy in this case.

Conclusion: Parents education and family support is vital in management of rare disease like GSD IIIa as part of a comprehensive medical care process.

Biography

Safa'a Al-Zeidaneen MSc, PhD, BCNSP.(01-04-1984) Assistant professor in field of pharmaco-nutrition in Al-Balqa Applied University. Have the American Board of Pharmacy Specialist: Nutrition Support Pharmacy (2016). Ph.D. in Human Nutrition and Dietetics (2014-2009). M.Sc. in Clinical Pharmacy (2008-2006). B.Sc. in Pharmacy (2006-2002).

Safaa84@bau.edu.jo.