

World Congress on
Nursing and Healthcare

November 21, 2022 | Webinar

Received date: 17-08-2022 | Accepted date: 19-08-2022 | Published date: 05-12-2022

Obstacles to Home-Based Dietary Management for Caregivers of Children with Citrin Deficiency: A Qualitative Study

Shuxian Zhang¹, Yun Du², Lingli Cai¹, Meixue Chen¹, Yuanzong Song², Lilan He², Ni Gong¹, Qingran Lin²

¹Jinan University, China

²The First Affiliated Hospital of Jinan University, China

Statement of the Problem: Dietary management is the most important and effective treatment for citrin deficiency, as well as a decisive factor in the clinical outcome of patients. However, the dietary management ability of caregivers of children with citrin deficiency is generally poor, especially in East Asia where carbohydrate-based diets are predominant. The aim of this study was to identify the difficulties that caregivers encounter in the process of home-based dietary management and the reasons responsible for these challenges.

Methodology & Theoretical Orientation: A qualitative study with a grounded theory approach was conducted to identify the reasons responsible for the irrational dietary management behaviors of caregivers. A semi-structured, in-depth interview was conducted with all participants, either face-to-face or online, according to the relevant interview guide.

Findings: Grounded theory was employed to identify three themes (covering 12 sub-themes) related to the dilemma of dietary management: dietary management that is difficult to implement; conflicts with traditional concepts; and the notion that children are only a part of family life. The first theme describes the objective difficulties that caregivers encounter in the process of dietary management; the second theme describes the underlying reasons responsible for the non-adherent behavior of caregivers; the third theme further reveals the self-compromise by caregivers in the face of multiple difficulties.

Conclusion & Significance: This study reflects the adverse effects of multi-dimensional contradictions on the adherence of caregivers to dietary management. These findings reveal that the dietary management of citrin deficiency is not only a rational process, rather it is deeply embedded in family, social and dietary traditions. The result of this study is helpful to improve the efficiency of dietary management in children with Citrin deficiency, as well as provides evidence for the formulation of dietary management strategies.

Recent publications

1. Okano Y, Ohura T, Sakamoto O, Inui A. Current treatment for citrin deficiency during NICCD and adaptation/compensation stages: strategy to prevent CTLN2. *Mol Genet Metab.* 2019;127:175–83. <https://doi.org/10.1016/j.ymgme.2019.06.004>.
2. Ohura T, Kobayashi K, Tazawa Y, Abukawa D, Sakamoto O, Tsuchiya S, Saheki T. Clinical pictures of 75 patients with neonatal intrahepatic cholestasis caused by citrin deficiency (NICCD). *J Inherit Metab Dis.* 2007;30:139–44. <https://doi.org/10.1007/s10545-007-0506-1>.
3. Saheki T, Kobayashi K, Terashi M, Ohura T, Yanagawa Y, Okano Y, Hattori T, Fujimoto H, Mutoh K, Kizaki Z, et al. Reduced carbohydrate intake in citrin-deficient subjects. *J Inherit Metab Dis.* 2008;31:386–94. <https://doi.org/10.1007/s10545-008-0752-x>.

Biography

Shuxian Yang is currently working at school of Nursing, Jinan University