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Research Week 2024

Impact of Medical formula shortage on patients with inborn errors of metabolism (IEM) and their dietitians

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Keywords

Medical formula/supplement shortage, Patients with IEM, psychosocial impact, dietitian-patient relations

Abstract

Since Feb. of 2022, patients with inborn errors of metabolism (IEM) suffered medical formula shortages due to an abrupt shut down of a major formula company in the US. To date, there has been no study of the shortage's impact on patients who are dependent on metabolic formulas. The goal of this project was to understand the nutritional and psychosocial impacts on patients with IEM and changes in patient-dietitian relations as a result of the unexpected formula shortage.

Two survey were set up and disseminated via REDCap to patients (18 years-old or older), parent/legal gurdian of patients in the US, from Dec.2023-Jan.2024. We collected 571 patient records in total, with 230 (40.3%) from the patient survey, 341 (59.7%) from the caregiver survey. Of those respective surveys, 139 (60.4%) patient surveys and 166 (48.7%) caregiver surveys were retained for analysis after dropping complete missingness. Data management and analyses were conducted with R software.

Logistic regression models were tested to investigate the association between household medical formula cutbacks, perceived weight impacts of the shortage, and the mediating effect of patient-dietitian relations. First, formula cutbacks were related to strained patient-dietitian relations (OR=2.94,95% CI=1.75,4.96). Secondly, strained patient-dietitian relations were associated with negative weight impacts(OR=2.85,95%CI=1.52,5.37). When predicting weight impact from formula cutbacks, patient-dietitian relations, and psychosocial impacts, cutting back on formula was not associated with negative weight changes(OR=1.84,95%CI=0.91,3.73). Finally, we found a significant indirect effect of formula cutbacks on negative weight impacts via strained patient-dietitian relations(OR=1.04,95%CI=1.01,1.07).

Our results suggest medical formula cutbacks due to the unexpected shortage may have had negative impacts on patients' weight perceptions via their increasingly strained dietitian relationships. Findings have implications for dietitians, such that they may benefit from maintaining positive relationships with patients during times of crisis, like a formula shortage. Such maintenance may improve nutritional outcomes for their patients.