Determining the continuing educational needs and learning preferences of dietitians related to managing patients with LC-FAOD

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Introduction and Purpose

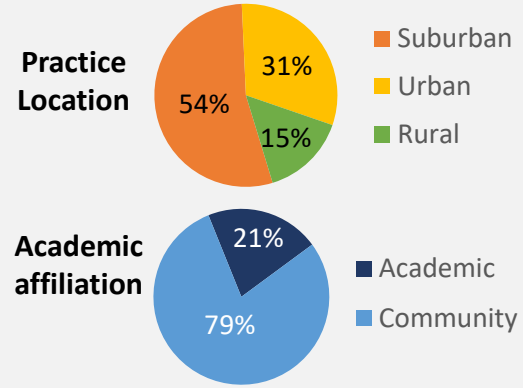
This study was conducted to assess current knowledge and experience of US-practicing dietitians in managing patients with long-chain fatty acid oxidation disorders (LC-FAOD) in order to determine areas of educational need for future continuing education to address.

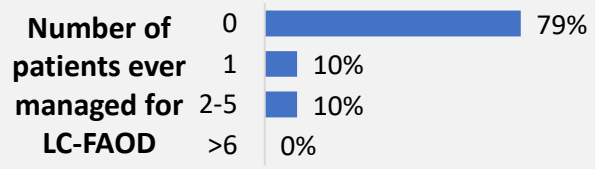
Methodology

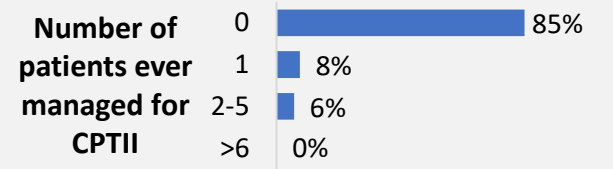
1. A survey instrument, including patient case scenarios with two of the most common forms of LC-FAOD (CPT-II and VLCAD), was designed to understand knowledge, attitudes, barriers, and experience related to managing patients with LC-FAOD.
2. The survey was developed and tested in collaboration with a dietitian experienced with managing patients with LC-FAOD.
3. The survey was distributed via email to 672 US-practicing dietitians during September 2019. Fifty-two dietitians completed the survey, of which 20% had previously managed a patient with LC-FAOD.
4. Descriptive data analysis and open-ended data coding was performed.

Respondent Demographics

	Dietitians (N = 52)
Number of patients seen per week (mean)	29 patients
Years since earning dietitian registration/nutrition license (mean)	19 years



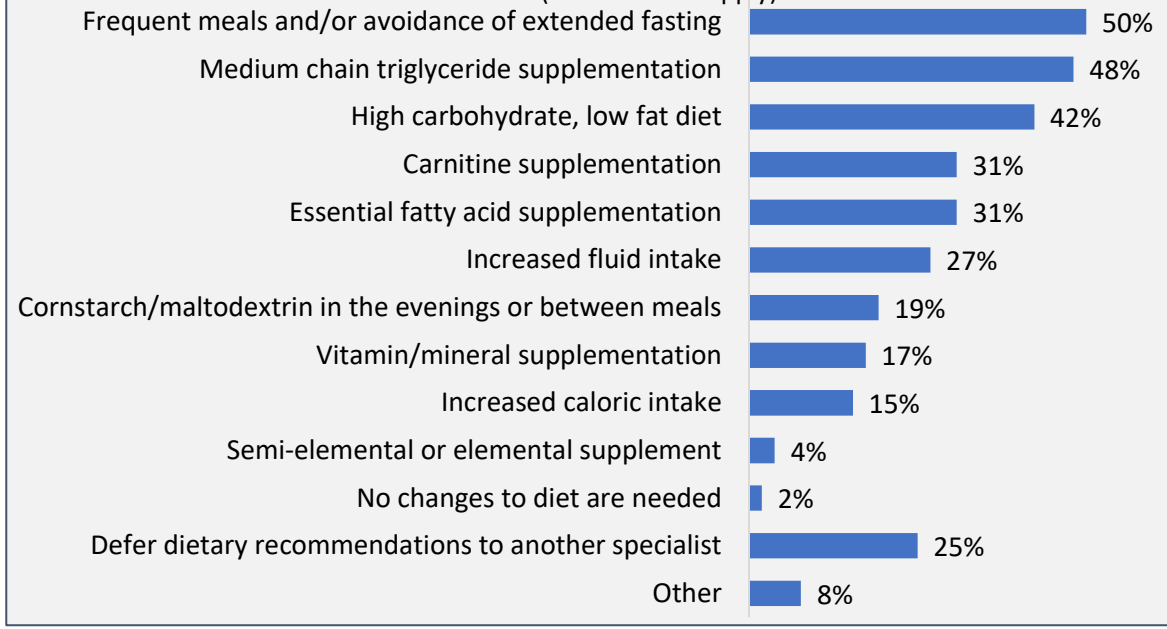




Dietary recommendations

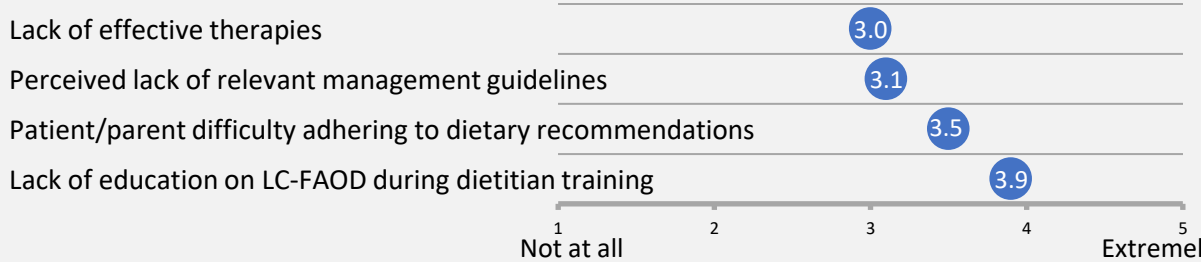
Case: An 18-month-old with very long chain acyl CoA dehydrogenase deficiency.

Dietary recommendations to prevent future acute episodes and complications of disease:
(select all that apply)



Barriers in Management

Perceived significance of barriers to optimal management of patients with LC-FAOD*



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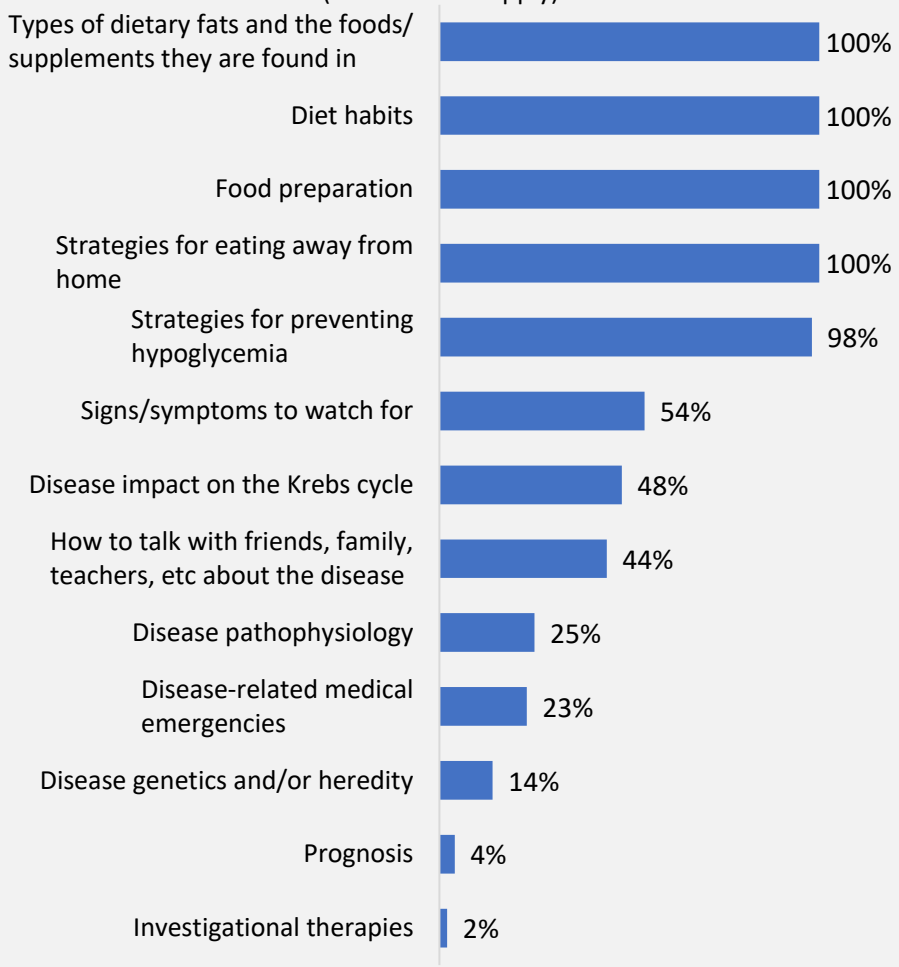
Patient Education

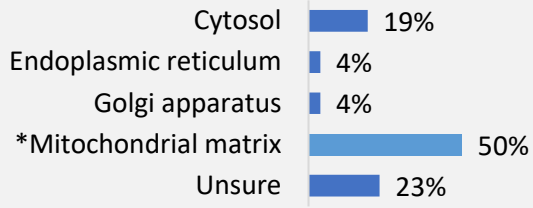
Case: 15-year-old with newly diagnosed CPTII deficiency

Would discuss the following with patient/parent:
(select all that apply)

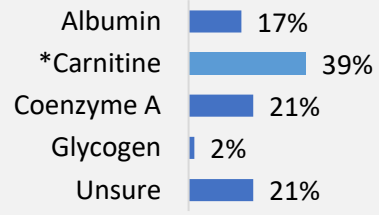


LC-FAOD Pathophysiology

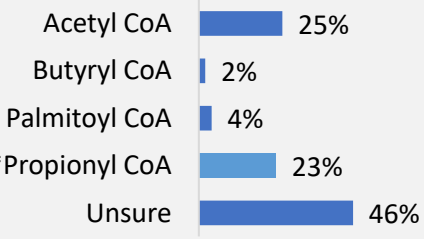
Where does fatty acid oxidation primarily take place?



Which is responsible for the transfer of long-chain fatty acids?

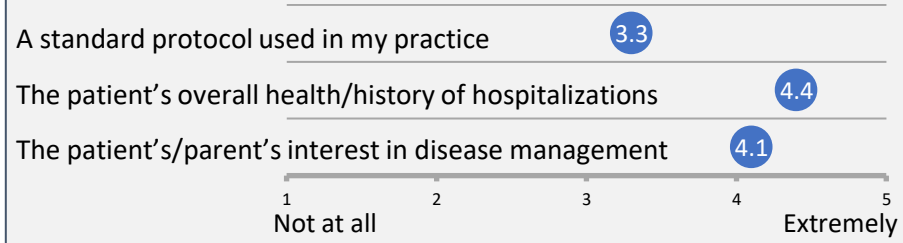


Which is produced by oxidation of odd-chain fatty acids that is NOT produced by the oxidation of even-chain fatty acids?

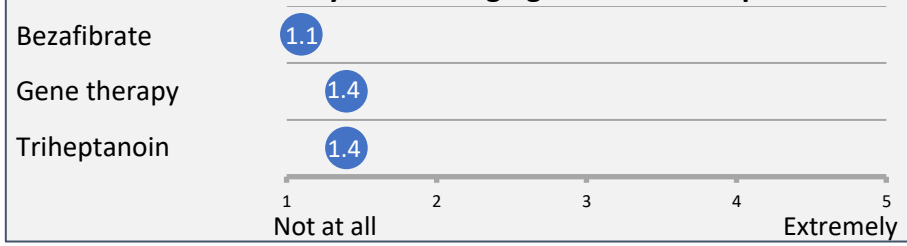


LC-FAOD Management

Importance in making dietary recommendations for patients with LC-FAOD

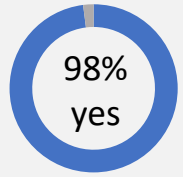


Familiarity with emerging LC-FAOD therapies

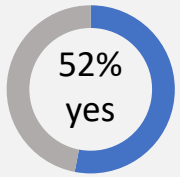


Continuing Education

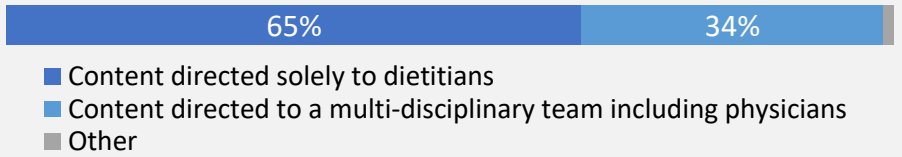
Do you access online continuing education?



Do you typically attend national meetings?



Preference for content of continuing education



Implications and Conclusion: Dietitians play a critical role in helping patients manage LC-FAOD through a modified diet and supplementation. However, dietitians report receiving limited training on LC-FAOD and many do not have experience managing patients with LC-FAOD. This study identified areas for future education including, nutritional management to prevent episodes of metabolic decompensation, awareness of disease pathophysiology, and appropriate referral to a metabolic center. Due to the small sample size, data were not evaluated based on those who have managed LC-FAOD versus not. However, results support that continuing education should be designed to address differences in learning preferences including online learning.