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

Emily Belcher[1], Wendy Cerenzia[1], Sylvie Stacy[1], Dustin Ensign[2], Tobin Chettiath, PharmD[3]

[1]CE Outcomes, LLC, Birmingham, AL USA; [2]Formerly at Ultragenyx Pharmaceutical Inc., Novato, CA USA; [3]Ultragenyx Pharmaceutical Inc., Novato, CA USA

Introduction and Purpose

Long-chain fatty acid oxidation disorders (LC-FAOD) are rare inborn errors of metabolism for which dietary management is the cornerstone of treatment. This study was conducted to assess current knowledge and experience of US-practicing dietitians in managing patients with LC-FAOD in order to determine areas of educational need for future continuing education to address.

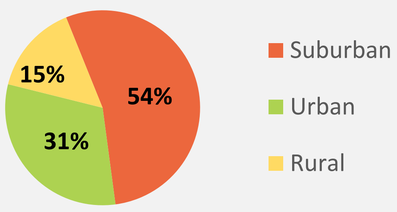
Methodology

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 LC-FAOD patients.
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.

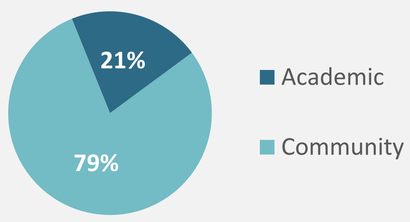
Respondent Demographics

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

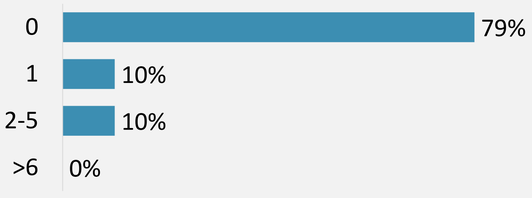
Practice Location



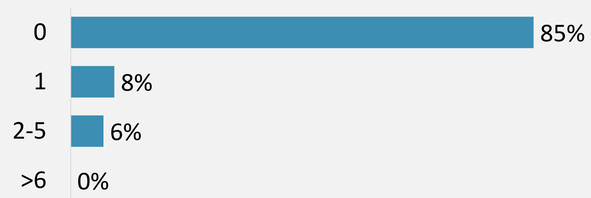
Academic affiliation



Number of patients ever managed for LC-FAOD



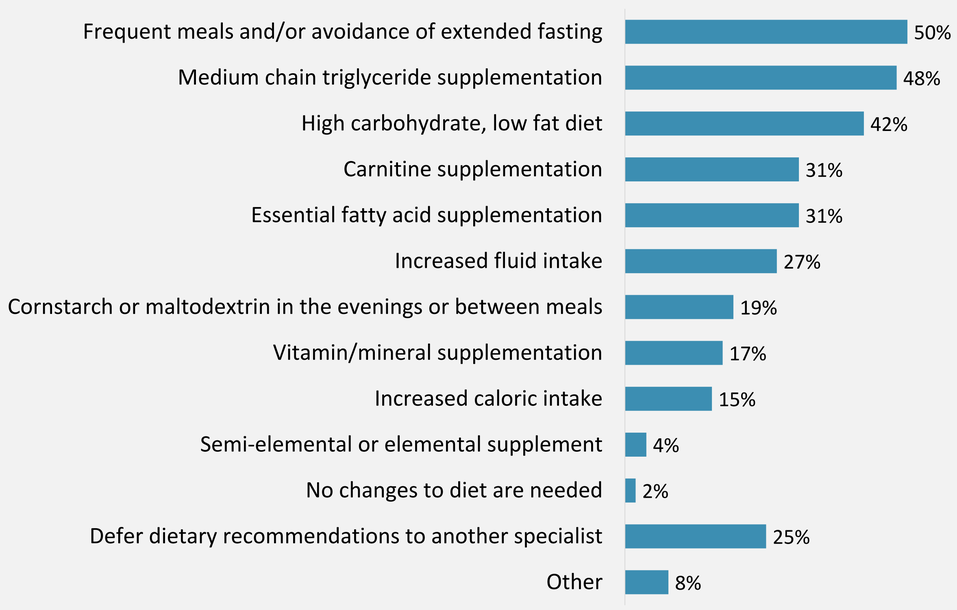
Number of patients ever managed for CPTII



Dietary recommendations

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

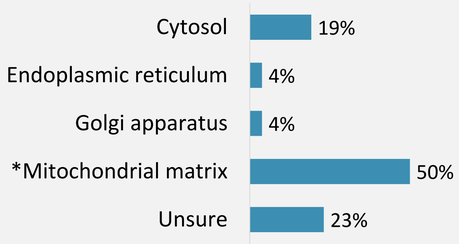
Dietary recommendations to prevent future acute episodes and complications of disease:



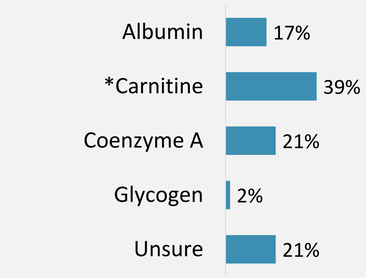
75% reported they would make dietary recommendations rather than deferring to another specialist. Of those making recommendations, the majority would advise avoidance of fasting; a low-fat diet, medium-chain triglyceride oil, or carnitine.

Familiarity with LC-FAOD Pathophysiology

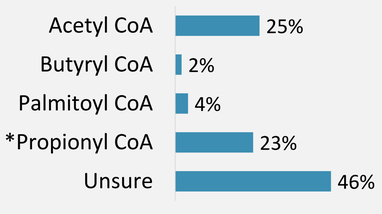
Where does fatty acid oxidation primarily take place?



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



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

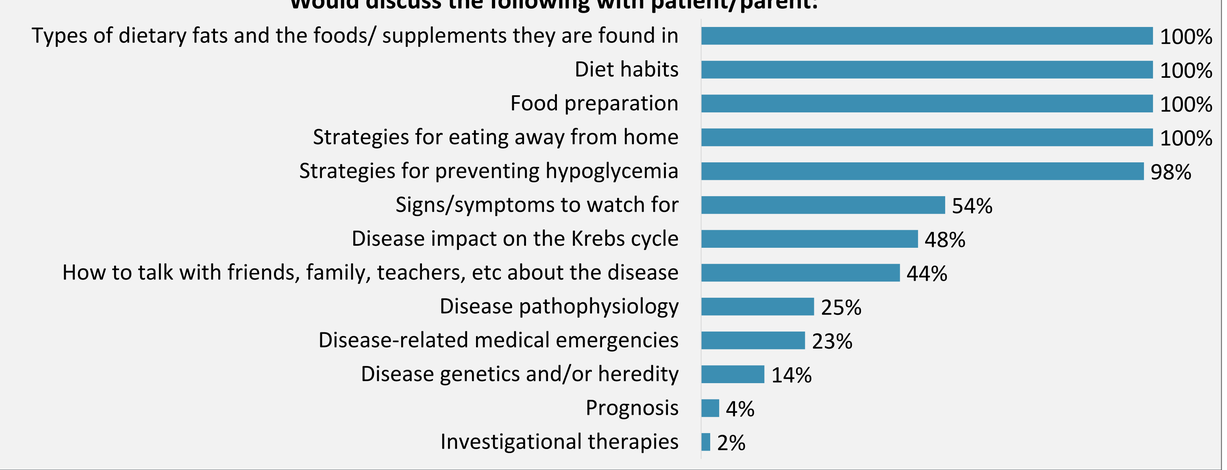


Many dietitians are unfamiliar with the normal processes of fatty acid metabolism, suggesting that future education should include concepts relating to both physiology and pathophysiology of LC-FAOD.

Patient Education

Case: 15-year-old with newly diagnosed carnitine palmitoyltransferase II deficiency

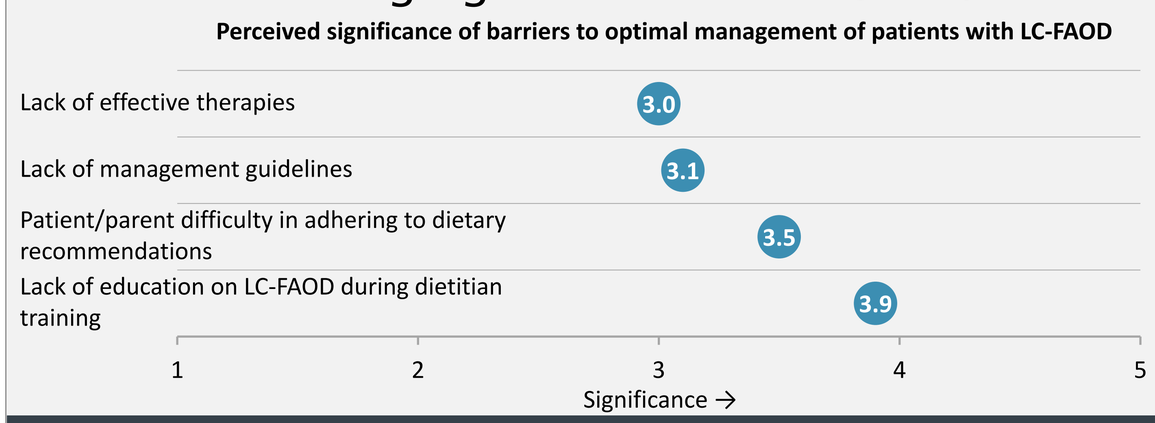
Would discuss the following with patient/parent:



Less than half of dietitians would discuss disease pathophysiology, impact on metabolism, and genetic basis with the patient diagnosed with LC-FAOD, which may be a reflection of lack of knowledge surrounding these topics.

Barriers in Managing Patients with LC-FAOD

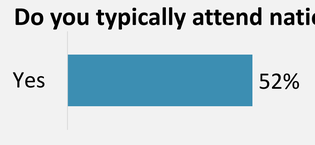
Perceived significance of barriers to optimal management of patients with LC-FAOD



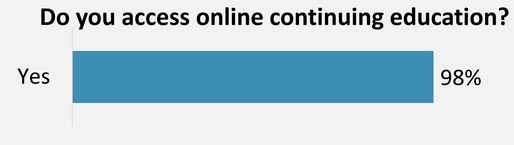
The most significant barrier to dietitians in optimally managing patients with LC-FAOD is the lack of education on LC-FAOD during dietitian training.

Continuing Education

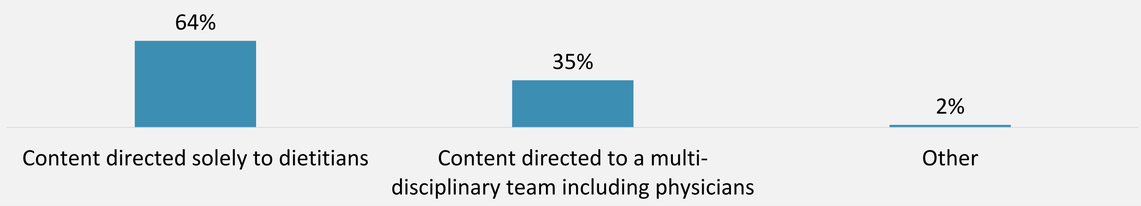
Do you typically attend national meetings?



Do you access online continuing education?



Which of the following is your preference for the content of continuing education?

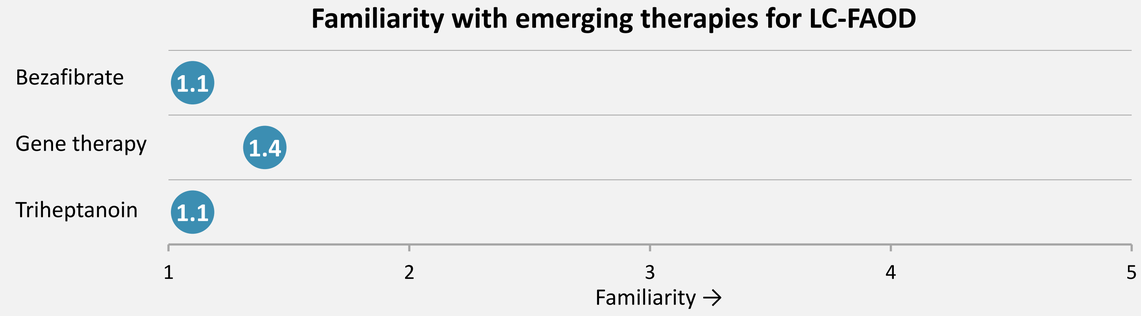


About half of respondents attend national meetings, while almost all (98%) access continuing education online. Further, 64% prefer content that is directed solely to dietitians while 36% prefer multidisciplinary content.

LC-FAOD Management

How important are each in making dietary recommendations for patients with LC-FAOD?

Familiarity with emerging therapies for LC-FAOD



Dietitians report placing more importance on an individualized approach to dietary management than on following a standard protocol. There is low familiarity with emerging therapies for LC-FAOD amongst dietitians.

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 directed toward dietitians, including awareness of disease pathophysiology and nutritional management to prevent episodes of metabolic decompensation. Due to small sample size, data were not evaluated based on those who have managed LC-FAOD versus those who have not. However, results support that continuing education should be designed to address differences in dietitians' learning preferences including online education.