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

<table>
<thead>
<tr>
<th>Dietitians (N = 52)</th>
<th>Practice Location</th>
<th>Academic Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients seen per week (mean)</td>
<td>29 patients</td>
<td>54% Suburban, 31% Urban, 15% Rural</td>
</tr>
<tr>
<td>Years since earning dietitian registration/nutrition license (mean)</td>
<td>19 years</td>
<td>79% Academic, 21% Community</td>
</tr>
<tr>
<td>Number of patients ever managed for CPTII</td>
<td>0</td>
<td>85%</td>
</tr>
<tr>
<td>Number of patients ever managed for VLCAD</td>
<td>0</td>
<td>85%</td>
</tr>
<tr>
<td>Number of patients ever managed for VLCAD</td>
<td>1</td>
<td>8%</td>
</tr>
<tr>
<td>Number of patients ever managed for VLCAD</td>
<td>2-5</td>
<td>6%</td>
</tr>
<tr>
<td>Number of patients ever managed for VLCAD</td>
<td>&gt;6</td>
<td>0%</td>
</tr>
</tbody>
</table>

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)
- Frequent meals and/or avoidance of extended fasting
- Medium chain triglyceride supplementation
- High carbohydrate, low fat diet
- Carnitine supplementation
- Essential fatty acid supplementation
- Increased fluid intake
- Cornstarch/maltodextrin in the evenings or between meals
- Vitamin/mineral supplementation
- Increased caloric intake
- Semi-elemental or elemental supplement
- No changes to diet are needed
- Defer dietary recommendations to another specialist
- Other

Barriers in Management

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

| Lack of effective therapies | 3.0 |
| Perceived lack of relevant management guidelines | 3.1 |
| Patient/parent difficulty adhering to dietary recommendations | 3.5 |
| Lack of education on LC-FAOD during dietitian training | Extremely |

*Survey participants could select up to three barriers as highly or extremely significant.

Not at all | 1 | 2 | 3 | 4 | Extremely
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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.