Nutrition with Gastrostomy Feeding Tubes for Amyotrophic Lateral Sclerosis in Canada

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ABSTRACT: Background: Amyotrophic lateral sclerosis (ALS) is a rapidly progressing degenerative motor neuron disease that results in significant muscle weakness. Defects in energy metabolism and difficulties in swallowing eventually lead to a reduction in body mass. Weight loss exacerbates symptoms and serves as an independent negative prognostic factor. Percutaneous endoscopic gastrostomy (PEG) is often inserted in patients with ALS to either supplement or replace oral feeding. However, the criteria for PEG placement and timing of insertion are important clinical decisions that have not been fully studied. Given the absence of guiding evidence, the aim of this project was to better understand how Canadian ALS clinics make decisions regarding gastrostomy feeding. Methods: ALS clinical directors across Canada were asked if they had written guidelines for timing of PEG insertion and if not, what criteria they use to make this decision. Responses from 10 of 17 centres contacted were received. Results: The approach to supplemental nutrition management in Canadian clinics varies in the absence of formal guidelines. Only one centre has a written set of centre-specific protocols in place. Most clinics considered some combination of respiratory decline, weight loss, dysphagia and/or patient readiness when reaching a decision. However, the absolute threshold and mechanism of measuring the individual criteria differed between clinics. Conclusions: Practices generally reflect international published recommendations but vary on the emphasis of specific criteria. Further research is required to determine the optimal timing and criteria to place gastrostomy feeding tubes in the ALS population.

AMYOTROPHIC LATERAL SCLEROSIS (ALS) is a progressive neurogenic disease resulting from the death of upper and lower motor neurons in the motor cortex, brain stem and spinal cord. This results in rapidly progressive muscle weakness, atrophy, and spasticity. Bulbar and respiratory muscle involvement can lead to dysphagia and dyspnea. In addition to the management of neuromuscular symptoms, nutritional and respiratory management are important aspects in the treatment of ALS.

Weight loss and dysphagia are frequent features of ALS and influence prognosis. The etiology of weight loss is multi-factorial. Upon initial diagnosis, patients with ALS are generally lean with a normal or low body-mass index (BMI). Patients then typically become malnourished and lose body fat as the disease progresses resulting in a further reduction in BMI.
The reason for progressive weight loss is two-fold; a decrease in energy intake is coupled with an increase in energy expenditure. Cranial bulbar muscle weakness producing dysphagia increases the risk for insufficient caloric intake; patients often eat more slowly and become fatigued during meals. Patients with ALS have a high basal metabolism rate contributing to weight loss. The mechanism leading to hypermetabolism is currently unknown, but has been demonstrated in both the sporadic and familial forms of ALS. A loss of body mass and malnutrition are associated with faster progression of the disease and are independent prognostic factors. Of additional concern, are the safety issues of aspiration and choking that result from dysphagia.

Nutritional interventions are integral to the management of ALS. At the onset of dysphagia the initial steps involve counseling by dieticians, modification of food and fluid consistency, prescription of high-protein and high-caloric supplements, and education of the patient on feeding and swallowing techniques. However, if significant caloric reduction or aspiration risk develops, a gastrostomy feeding tube is often introduced. Both the American Academy of Neurology (AAN) and the European Federation of Neurological Sciences (EFNS) have published guidelines that recommend the placement of percutaneous endoscopic gastrostomy (PEG) in patients with ALS in order to supplement nutrition. This recommendation was based on evidence that nutritional supplementation using PEG was helpful for stabilizing weight loss. The prevention in weight-loss provided by PEG likely translates to a survival benefit but there is not enough data to quantify to what extent this occurs.

In addition to general procedural risks for PEG, such as wound infection, bleeding and ulceration, there are risks specific to the ALS population. Patients with respiratory muscle impairment undergoing sedation may have aspiration with PEG insertion. Diaphragmatic weakness causes a “high-riding” stomach, in which the stomach lies under the ribs, which can increase the difficulty of tube insertion. Furthermore, ALS is known to be a rapidly progressing disease. Thus the timing and the method of insertion are important considerations when using gastrostomy feeding in the management of ALS. However, both these topics are under-studied. As a result, the AAN and EFNS have each stated that there is insufficient evidence to support or refute specific timing of PEG insertion in patients with ALS. That said, the AAN practice parameter does suggest consideration of dysphagia, weight loss and respiratory function, measured as forced vital capacity (FVC), in the decision making process.

Given the lack of evidence to rigorously guide decisions and the presence of international guidelines, we wished to determine how Canadian ALS clinics make decisions regarding the timing and placement of gastrostomy feeding tubes in patients with ALS.

**METHODS**

Through email and paper correspondence we asked the medical directors of Canadian ALS clinics about their approach to gastrostomy feeding in patients with ALS. This information was also requested in the newsletter of the Canadian ALS Research Network (CALS). We asked two questions. Does the clinic have written centre-specific protocols to guide the timing of PEG placement in ALS patients? If a protocol existed we requested that they forward us any relevant documents. For centres that did not have written protocols we asked what steps are taken to determine candidacy and timing for placement of gastrostomy feeding tubes in lieu of formal guidelines. The responses were aggregated in order to compare and contrast the practices across clinic sites.

**RESULTS**

A total of seventeen Canadian ALS clinics were contacted and ten centres provided a response. The results of the survey are summarized in Table 1. The open-ended questions led to variable amounts of detail in individual responses. One centre had centre specific written guidelines whereas the other nine did not. One of the ten responding centres was a francophone clinic. The remaining nine clinics were English speaking. All of the clinics were hospital affiliated. Nine of the ten responses commented on key decision-making criteria they consider in the decision to insert gastrostomy feeding tubes.

Most centres used a decline in respiratory function, dysphagia, weight loss or some combination of all three. Six clinics explicitly stated that they measure and consider a dropping FVC, a marker of respiratory decline, as a factor prompting the decision for feeding tube insertion. The FVC chosen ranged from >70% (with rapid decline) to <30% in special cases. One clinic reported inserting feeding tubes after tracheotomy and ventilation but stated this was a rare occurrence. Most recommend gastrostomy feeding at around FVC 50-60% of predicted.

Swallowing impairment was reported as an important factor in decision-making by seven clinics but there was variation in how this was applied. Some clinics considered the number of aspiration events, others monitored prolonged mealtimes and patient and/or family concerns about swallowing. Two centres report regular use of swallowing assessments, either modified barium swallow or fiberoptic endoscopic evaluation of swallowing (FEES) to determine the extent of dysphagia and used this in their clinical decision making process. Five clinics reported weight loss in conjunction with, or independent of, other clinical factors could result in a referral for a feeding tube. Three centres used a quantifiable amount (>10% weight loss or <18.5 kg/m² BMI in one centre and >10% weight loss in two centres) as triggering a need for gastrostomy feeding. Two others stated weight loss was considered but done through subjective assessment such as patient report. Two centres explicitly stated that they follow published guidelines for management of gastrostomy feeding in ALS.

Psychological readiness to have a tube placed was commented on by three sites as significantly influencing the recommendation for tube placement. Some centres note that discussions regarding future gastrostomy feeding are brought up early in the course of the disease to prepare the patient for future decision-making. Three sites reported that they frequently insert tubes well before oral feeding is impacted — sometimes more than a year in advance. This was generally due to reducing respiratory function in the absence of swallowing impairment. One clinic emphasized they recommended advanced health care directives to their patients that specifically include tube feeding decisions.

The method of feeding tube insertion varied considerably from centre to centre. Three centres report using PEG, three centres radiologically inserted gastrostomy (RIG) and four did not comment. One centre noted that the expertise for RIG was not available, hence all procedures are PEG. One centre requires admission to hospital for the procedure, but that was not a general requirement for the centres that reported.

**DISCUSSION**

Weight loss and aspiration risks are concerns that can be adequately managed by gastrostomy feeding. The timing and criteria
Table 1: Canadian ALS clinic survey responses identifying which clinical factors prompt a referral for insertion of a feeding tube.

<table>
<thead>
<tr>
<th>Site</th>
<th>Protocol</th>
<th>FVC</th>
<th>Dysphagia</th>
<th>Weight loss</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No</td>
<td>50-55%</td>
<td>Yes</td>
<td>&gt;10% of weight loss</td>
<td>Radiologic</td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td>&lt;50% but will insert down to 30%</td>
<td>Yes - assessed by MBS, FEES or patient report</td>
<td>When significant</td>
<td>Radiologic</td>
</tr>
<tr>
<td>3</td>
<td>No</td>
<td>&gt;50%</td>
<td>Yes</td>
<td>Endoscopic</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>No</td>
<td>FVC &lt;60% OR FVC &gt;70% with one or more of the following: rapid decline in FVC, low ALSFRS score OR drop of &gt;1 point per month, indicated wish for aggressive ventilation</td>
<td>Yes - including poor bulbar function at any FVC, prolonged meal time, ending meal prematurely due to fatigue</td>
<td>&gt;10% weight loss OR BMI &lt;18.5 at any FVC</td>
<td>Radiologic</td>
</tr>
<tr>
<td>5</td>
<td>No</td>
<td>&gt;50%</td>
<td>Yes</td>
<td>Endoscopic</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>No</td>
<td>&lt;60% with dysphagia OR respiratory symptoms in the absence of dysphagia</td>
<td>Yes - assessed by MBS or patient report</td>
<td>Endoscopic</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>No</td>
<td>May prompt referral</td>
<td>Radiologic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>No</td>
<td>&gt;50%</td>
<td>Yes</td>
<td>Endoscopic</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>No</td>
<td>&lt;10% of weight loss</td>
<td>Endoscopic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>No</td>
<td>&gt;10% of weight loss</td>
<td>Radiologic</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: Clinic names have been removed. A blank entry denotes the respondent did not comment on this topic. FVC: Forced vital capacity. BMI: Body mass index kg/m². ALSFRS: ALS Functional Rating Scale. MBS: Modified barium swallow. FEES: Fiberoptic endoscopic evaluation of swallowing.
further research to understand what place they should take in the decision regarding gastrostomy feeding. Indicators of nutritional deficiency variably applied were identified as key elements of the evaluation of need for gastrostomy feeding in half of our reporting clinics, potentially reflecting uncertainty in how to integrate this information into the decision making process.

Though ALS clinics in Canada are known to be interdisciplinary, our study did not ask whether clinics have dedicated gastroenterologists, dieticians, or speech language pathologists available during the decision making process. This is of relevance as studies have suggested inclusion of inter-disciplinary nutrition support teams results in higher rates of insertion. Once the decision is made to insert a feeding tube, dieticians and speech language pathologists help guide the choice of formula feed and infusion rate of feeds. This is another area of decision-making language pathologists help guide the choice of formula feed and decision is made to insert a feeding tube, dieticians and speech language pathologists help guide the choice of formula feed and infusion rate of feeds. This is another area of decision-making where there is a role for qualitative patient perspectives. To date, there is little published evidence regarding quality of life with respect to PEG insertion in patients with ALS. Preliminary research suggests that a feeding tube does give the patient a greater sense of control but may lead to increased anxiety. This might be of particular relevance, as there seems to be a trend to recommend PEG earlier than required to avoid potential complications of late-placement. More quality of life studies are needed. Our study focused on the medical factors influencing the decision-making process for a referral for a feeding tube. For placement to take place, it requires a separate decision-making process on the part of the patient. Growing literature suggests that factors involved in the patient’s decision are even more complex and multi-faceted.

Such decisions may benefit from an individualized approach to referral rather than an algorithmic approach. The patient experience before, during and after insertion of a gastrostomy tube is an essential component of developing guidelines for what is essentially a palliative procedure. Information from patients about perceived nutritional needs; desires regarding timing of tube placement; benefits and difficulties noted after tube placement would all be important for development of effective guidelines. These questions may be answered by using qualitative research techniques.

**Disclosures**

Timothy Benstead, Caitlin Jackson-Tarlton, and Desmond Leddin do not have anything to disclose.

**References**


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