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Original article

Survey of current enteral nutrition practices in treatment of amyotrophic lateral sclerosis

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SUMMARY

Background and aims: Enteral nutrition (EN) is commonly prescribed for dysphagia and weight loss in amyotrophic lateral sclerosis (ALS), but there are currently no ALS-specific EN guidelines. We aimed to survey current practices prescribing EN to ALS patients.
Methods: An online survey was distributed using list servers administered by the Academy of Nutrition and Dietetics (AND), Muscular Dystrophy Association (MDA), and ALS Association (ALSA).
Results: A total of 148 dietitians, nurses, and physicians participated in the survey, of whom 50% were dietitians and 68% were associated with an ALS clinic. Only 47% of respondents reported their patients to be fully compliant with EN recommendations. Side effects (fullness, diarrhea, constipation, and bloating) were the most important reason for patient noncompliance, followed by dependence on caregivers. By contrast, only 3% of providers rated depression/hopelessness as the most important reason for non-compliance. Half of those surveyed reported that more than 25% of patients continued to lose weight after starting EN.
Conclusions: Our survey results show a high frequency of gastrointestinal side effects and weight loss in ALS patients receiving EN. These findings may be limited by sampling error and non-response bias. Prospective studies are needed to help establish EN guidelines for ALS.

1. Introduction

Amyotrophic lateral sclerosis (ALS, or “Lou Gehrig’s disease”) is a neurodegenerative disease characterized by the progressive loss of upper and lower motor neurons. Patients typically survive 2 to 5 years from symptom onset until they reach respiratory paralysis and death.

Because of problems with dysphagia, muscle degeneration, and increased energy expenditure, ALS patients frequently have difficulty maintaining their body weight and nutrition status. Patients not using enteral nutrition have been shown to consume on average 10–19% less than their recommended daily calories.[1,2] This diet deficit is correlated to their degree of weight loss and reduction in body fat percentage.[1,3] Because weight is a prognostic factor in disease progression, weight maintenance is important both in preventing malnutrition and delaying physical decline.[1,2,4–6]

Abbreviations: AND, Academy of Nutrition and Dietetics; ALS, amyotrophic lateral sclerosis; ALSA, Amyotrophic Lateral Sclerosis Association; BMI, body mass index; EN, enteral nutrition; MDA, Muscular Dystrophy Association; PEG, percutaneous endoscopic gastrostomy; RIG, radiologically inserted gastrostomy.

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Enteral nutrition (EN) administered via a percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG) device provides long-term nutritional support for patients suffering from dysphagia. According to the American Academy of Neurology (AAN) 2009 Practice Parameter update: "Enteral nutrition administered via PEG is probably effective in stabilizing body weight/body mass index".[7] The AAN guidelines reviewed two Class II studies in which EN was shown to stabilize body weight in patients receiving PEG compared to continued weight loss in controls who refused PEG.[7] The European Federation of Neurological Societies (EFNS) guidelines from 2012 state that "PEG improves nutrition, but there is no convincing evidence that it prevents aspiration or improves quality of life or survival".[8] Despite the potential benefits of EN treatment in the care of ALS, there are currently no prospective randomized studies of the use of EN in ALS. While the AAN and EFNS guidelines recommend early insertion of feeding tubes before respiratory status has declined to 50% of predicted forced vital capacity, there are no guidelines regarding the best method of EN administration, target body weight, type of nutritional supplements, best method to calculate daily caloric requirements, or frequency of monitoring after EN initiation. In part as a result, EN is frequently underutilized in treatment of ALS.[9] The aim of this study was to survey current EN practices of ALS providers in order to begin to address these important questions.

2. Methods

2.1. Participants

Partners Healthcare Institutional Review Board approval was obtained for the online survey and all recruitment letters. Participants were invited to participate in the online survey if they were active in prescribing tube feedings to patients with ALS. Invitations were sent through list servers administered by the Academy of Nutrition and Dietetics (AND), Muscular Dystrophy Association (MDA), and ALS Association (ALSA). These associations primarily serve the United States and Canada. Participants who filled out the survey were entered into a drawing for an iPad2. Participants were assured that their answers would be confidential, and that their name and contact information would only be used for the purposes of entering into the drawing. A total of 148 dietitians, nurses, and physicians participated in the survey.

We developed a 19 question survey designed to query current clinical practices and experiences in prescribing enteral nutrition to patients with ALS (see Online supplementary material). The survey was developed in conjunction with several dietitians and physicians involved in treating ALS (see author list) and pilot tested by dietitians not involved in the development of the survey. The 10 minute web-based survey was administered through LimeSurvey from the period of August through November 2011. The survey was divided into 5 parts. Part 1 consisted of questions about their work facility, experience with ALS and role in prescribing EN. Part 2 asked participants about the different EN formulas and routes of administration. Part 3 involved questions about problems with EN tolerability and compliance. Part 4 addressed how participants calculate the caloric needs and weight goals of their patients. Part 5 asked about how participants monitor their patients' weights and adjust their care to address weight loss. Participants were also invited to provide free-text answers regarding their experience with treating ALS.

2.2. Data management and analysis

The survey was administered on the website LimeSurvey (http://www.limesurvey.org/), an open source software hosted by Partners' internal datacenter. This website was chosen over other 3rd-party survey hosting websites because of its security and Secure Sockets Layer (SSL) encryption. Analysis of results was done using LimeSurvey, as well as on Microsoft Office Excel and SAS 9.2 (SAS Institute, Cary, NC). A separate sub-analysis of dietitians treating >20 patients a year was also performed to look at concordance or deviation from all participants.

3. Results

3.1. Demographics

148 health workers responded to this survey (Table 1). Dietitians encompassed the largest proportion of participants, followed by physicians and nurses. The majority of participants worked at MDA, ALSA or other ALS clinics, followed by in-patient and out-patient hospitals. Most participants reported treating more than 30 ALS patients a year. Of those who answered the survey question, 23.2% reported being involved only in the initial recommendations for enteral nutrition, while most reported being involved in long term follow-up care (76.8%).

3.2. Methods of administration

Bolus feeding was the most commonly used method of administering EN (53.4%), followed by gravity feeding (23.3%). Other methods such as pump feeding (6.9%) and combinations of bolus and gravity (16.4%) were used less often. Bolus feeding was associated with lower rates of patient compliance compared to gravity feeding (17.0% versus 7.4% of participants reported only 25–50% compliance rates, Fisher's Exact Test $p = 0.008$). However, gravity feeding was associated with a higher frequency of diarrhea than bolus feeding (48.2% versus 26.5%, $p = 0.03$). No other gastrointestinal side effects were reported more frequently in one method of administration over another.

3.3. Calculation of caloric requirements and ideal body weight

In order to calculate the caloric requirements of their patients, participants predominately used the kcal/kg body weight equation (58.8%) or Harris-Benedict equation (27.7%). The Mifflin St. Jeor equation (8.8%) and indirect calorimetry (5%) were rarely used as first choice options, but were sometimes used as second or third

Table 1
Participant demographics.

Demographics	*N* (%)
Profession	
Dietitian	74 (50)
Physician	19 (12.8)
Nurse	35 (23.7)
Missing	20 (13.5)
Workplace (multiple answers allowed)	
MDA/ALSA clinic	100 (67.6)
In-patient hospital	42 (28.4)
Out-patient hospital	19 (12.8)
Homecare Company	5 (3.4)
Other	16 (10.8)
ALS patients treated annually	
1–10	16 (10.8)
11–20	14 (9.46)
21–30	16 (10.8)
>30	89 (60.1)

Participants in the nutritional survey by licensure, type of practice, and number of ALS patients treated annually. Under type of practice, participants were allowed to choose more than one answer. ALS: amyotrophic lateral sclerosis; ALSA: Amyotrophic Lateral Sclerosis Association; MDA: Muscular Dystrophy Association.