ORIGINAL ARTICLE

Oropharyngeal Dysphagia in Patients Affected by Amyotrophic Lateral Sclerosis

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Abstract

Aim: The purpose of this study was to describe our experience in the observation of oropharyngeal dysphagia with endoscopic evaluations in patients suffering from amyotrophic lateral sclerosis (ALS).

Patients and methods: We conducted a retrospective study of patients suffering from ALS managed with serial functional endoscopic evaluation of swallowing. Patients were divided into a no-aspiration group and an aspiration group based on Penetration Aspiration Scale scores obtained during endoscopic evaluation of swallowing.

Setting: Tertiary Referral Center for Rehabilitation. Dysphagia was classified according to American Speech Language Hearing Association-National Outcome Measurement System levels.

Results: A total of 32 patients were examined, and different progression patterns of dysphagia were observed.

Clinical evidence: A nonlinear evolution of dysphagia, with a plateau phase in patients with bulbar-onset type ALS, was observed.

Keywords: Amyotrophic lateral sclerosis, Dysphagia, Fiberoptic endoscopic evaluation of swallowing, Laryngoscopy, Otolaryngology, Swallowing.

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Summary

- Our study highlighted that there is a variable difference in the temporal progression of dysphagia between patients affected by amyotrophic lateral sclerosis (ALS).
- The evaluation of the American Speech-Language-Hearing Association (ASHA) National Outcome Measurement System (NOMS) score showed a different deterioration of swallowing over time.
- Patients affected by spinal onset ALS tended to have a different worsening of the PAS score over time compared to bulbar clinical history.
- The findings of this study also suggest that the progression of dysphagia in ALS is not regular, and slowdown phases can be identified.
- By monitoring the patient through periodic Fiberoptic Endoscopic Evaluation of Swallowing (FEES), together with a multidisciplinary pool of experts in their respective fields, an attempt could be made to preserve oral feeding to deliver a better quality of life to these patients.

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Introduction

Amyotrophic lateral sclerosis is a progressive neurodegenerative condition that affects both upper and lower motor neurons responsible for controlling the muscles of the limbs, trunk, bulbar region, and respiratory system.[1] It is the most prevalent motor neuron disease in adults, with an incidence rate of 2 per 1,00,000 individuals and a prevalence of 5.4 per 1,00,000.[2] Amyotrophic lateral sclerosis typically manifests in mid-to-late adulthood, leading to progressive muscle weakness and atrophy. Involvement of the respiratory muscles significantly limits survival, with most individuals living only 2–4 years after the onset of symptoms. However, a small percentage (about 5–10%) may survive for 10 years or longer.[2,3]

The majority of ALS cases (approximately two-thirds) begin with spinal onset, where progressive muscle weakness is the initial sign.[1] The remaining one-third present with bulbar onset, leading to early difficulties with swallowing or speaking.[4] In addition to these common forms, recent research has identified other variants, such as mixed onset (spinal and bulbar), thoracic onset, and cases with concurrent dementia.[5–7]

As previously mentioned, bulbar involvement leads to the development of oropharyngeal dysphagia (OD) and dysarthria, which are present early on, and in spinal-onset ALS, these symptoms typically emerge as the disease progresses. Unfortunately, the presence of OD not only worsens the patient's quality of life and leads to social isolation, but it also introduces severe complications like weight loss, malnutrition, extended mealtimes, fatigue during eating, choking, food impaction in the throat, difficulty swallowing saliva, and aspiration pneumonia.[8,9] Furthermore, malnutrition is considered an independent risk factor for increased mortality in ALS patients.[2–9]

Currently, there is no cure for ALS; however, some treatments, such as riluzole and non-invasive ventilation may help prolong survival.[8] The management of ALS is a multidisciplinary effort that involves neurologists, pulmonologists, gastroenterologists, rehabilitation specialists, palliative care teams, physiotherapists, speech-language pathologists (SLPs), occupational therapists, nutritionists, and psychologists.[8,9] However, otolaryngologists are often not involved in the management of ALS until more invasive measures, such as tracheostomy, are considered, despite evidence that swallowing involves intricate communication between the central nervous system and the pharyngo-laryngeal region.[10]

Research has demonstrated that swallowing involves a Central Pattern Generator (CPG) network, where voluntary swallows are initiated by a convergence of descending cortical inputs and sensory feedback from the oropharynx. Reflexive swallows, on the other hand, are triggered solely by sensory input and the CPG originating in the pontobulbar region.[11] This understanding highlights the importance of collaboration between neurologists and ENT specialists in managing ALS patients with swallowing difficulties.

To assess dysphagia, diagnostic tools such as Videofluoroscopic Swallowing Studies (VFSS), FEES, and oropharyngo-esophageal scintigraphy are commonly used.[12–14] Although many clinicians consider VFSS and FEES to be interchangeable, a study by Kelly et al. in 2006 showed that FEES is more effective at detecting pharyngeal residue and aspiration compared to videofluoroscopy.[15]

Objective

The purpose of this study is to observe OD in ALS patients.

Patients and Methods

The aim of this study is to investigate OD in patients diagnosed with ALS.

Study Design and Setting

This study was a retrospective, observational, non-pharmacological investigation. We examined patients diagnosed with ALS and OD who were managed in our department between January 2021 and July 2023.

Participants

All participants had a diagnosis of ALS (either definite or probable) according to the revised El Escorial Criteria, with diagnoses made by neurologists specialized in ALS.[16] Each patient underwent a thorough ENT assessment, which included a review of their clinical history followed by oropharyngolaryngoscopy. We evaluated oral functions, including mouth opening, tongue mobility, soft palate elevation, pharyngeal reflex, voluntary cough, laryngeal cough reflex, salivation levels, and dental health. Amyotrophic lateral sclerosis patients were categorized based on the type of onset: spinal or bulbar.

Table 1: General features of the total sample and stratified by type of ALS at time 0

Features	*Total sample N (%)*	*Bulbar type N (%)*	*Spinal type N (%)*
Gender			
M	17 (53.1)	4 (33.3)	13 (65.0)
F	15 (46.9)	8 (67.7)	7 (35.0)
Age (years) median (IQR)	68.0 (57.3–73.0)	71.0 (64.0–75.0)	61.5 (52.3–70.8)

In total, 32 ALS patients with OD were included. Of these, 12 (37.5%) had bulbar-onset ALS and 20 (62.5%) had spinal-onset ALS. No mixed-onset cases were observed. The cohort consisted of 53.1% males, and the median age was 68 years (range: 57.3–73). General characteristics of the sample at baseline (T0) are summarized in Table 1.

A comprehensive endoscopic evaluation of the rhino-pharyngo-laryngeal regions was performed for all patients, including FEES. For video recording, we used the DIVAS 2.8 software by XION. Fiberoptic endoscopic evaluation of swallowing was conducted following a modified protocol based on De Stefano.[17,18] During the initial FEES exam at T0, participants underwent three trials with thin liquids, three with thick liquids, followed by a small bite of banana (soft solid) and cracker (hard solid). Liquids and foods were selected according to the International Dysphagia Diet Standardization Initiative levels 0–4 and 6–7.[17–19]

Each liquid trial consisted of 10 cc of water, apple sauce, or aquagel (Nestlé Nutricia Nutilis®), with blue food coloring added. Subsequent swallowing evaluations focused on the same food consistencies approved in prior assessments. No topical anesthetics were used during FEES, though a water-soluble lubricant was applied to reduce patient discomfort.

Swallowing was classified using the Penetration Aspiration Scale (PAS), which ranges from 1 to 8.[20] After the initial FEES assessment (T0), patients were followed up with periodic evaluations every 4–6 months (T1, T2, T3) to monitor the progression of dysphagia. Adjustments to diet and the recommendation of safe swallowing postures were made as needed. Patients were excluded from the study if swallowing function deteriorated to the point where an alternative feeding method was required, or if the nutritionist deemed a significant decline in clinical status, despite residual swallowing capability.

When deemed necessary by the nutritionist, patients were recommended for percutaneous endoscopic gastrostomy (PEG) or other alternative feeding methods.

At the end of each follow-up FEES evaluation (T0, T1, T2, T3), the severity of OD was classified using the ASHA NOMS swallowing scale, which helped track the progression of dysphagia.[21] Table 2 summarizes PAS and ASHA NOMS scores at T0, stratified by ALS type.

A trained SLP with expertise in dysphagia provided individualized rehabilitation. The duration and frequency of rehabilitation sessions were tailored to each patient's clinical needs and availability. Treatment focused on compensatory strategies, such as prolonged chewing, head tilt, and chin tuck. Behavioral modifications were recommended, including taking smaller bites

Table 2: Scores of PAS and ASHA NOMS of the total sample and stratified by type of ALS at time 0

Features	*Total sample N (%)*	*Bulbar type N (%)*	*Spinal type N (%)*
FEES			
PAS 1	2 (6.3)	0 (0.0)	2 (10.0)
PAS 2	18 (56.3)	9 (75.0)	9 (45.0)
PAS 3	9 (28.1)	2 (16.7)	7 (35.0)
Missing	3 (9.4)	1 (8.3)	2 (10.0)
ASHA NOMS			
4	4 (12.5)	0 (0.0)	4 (20.0)
5	8 (25.0)	4 (33.3)	4 (20.0)
6	16 (50.0)	7 (58.3)	9 (45.0)
7	1 (3.2)	0 (0.0)	1 (5.0)
Missing	3 (9.3)	1 (8.4)	2 (10.0)

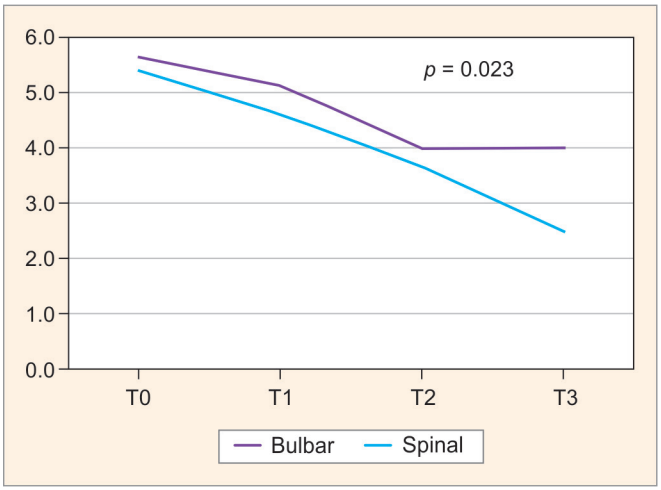

Fig. 1: Illustrates the trend of the average value of the ASHA NOMS stratified by type of ALS. At T3, the bulbar type patients seem to attain a plateau

and sips, sitting upright during meals, avoiding talking while eating, and being mindful of each swallow. Additionally, patients were advised to consume smaller, more frequent, hypercaloric meals daily, with guidance on food and liquid types.

Bias

This study is subject to several potential biases, including selection, outcome, and measurement biases. To minimize selection bias, we included only patients diagnosed with definite or probable ALS based on the revised El Escorial Criteria. However, it is important to note that the sample was drawn from a single, geographically limited area.

Outcome bias could arise from misclassification, such as an unknown number of patients who may have sought care at other centers outside the region where the study was conducted.

Measurement bias is unlikely in this study, as OD and its progression were objectively confirmed using instrumental endoscopy.

Study Size

As this was an observational study, determining a sample size was not applicable.

Statistical Methods and Variables

Quantitative variables were presented as means ± standard deviations (SD) or as medians with interquartile ranges (IQR), depending on their distribution, which was assessed using the Shapiro–Wilk test. Categorical variables were expressed as frequencies and percentages. Patients were categorized based on the type of ALS, and differences between groups were analyzed using the *t*-test or the non-parametric Mann–Whitney *U* test for continuous variables, and the Pearson chi-squared test for categorical variables. Statistical analyses were conducted using IBM® SPSS Statistics v20.0 (SPSS Inc, Chicago, Illinois, USA). Statistical significance was set at $p < 0.05$. This study was conducted in accordance with the STROBE guidelines for reporting observational studies.[22] Ethical standards were strictly adhered to, following the Declaration of Helsinki. The study was approved by our Ethical Committee (Protocol No. 1976/CEL).

Results

Outcome Data and Main Results

Twenty-three patients (71.9%) were recommended to undergo a PEG, 69.6% of these were dysphagic patients who had an initial clinical history attributable to spinal forms of ALS.

These patients tended to have a different worsening of the PAS score over time compared to bulbar clinical history subjects, and the difference was statistically significant ($p = 0.041$ T1 vs T2, $p = 0.018$ T2 vs T3).

There was no statistically significant difference between those who underwent a rehabilitation intervention and those who did not ($p = 0.092$).

Evaluation of the ASHA NOMS score showed its deterioration over time. In particular, 13 (56.5%) of the total 23 subjects re-evaluated at T1 had a worsening of the score. Meanwhile, the remaining 10 subjects, who had a constant score at T1, had a worsening in later times. Figure 1 illustrates the trend of the average value of the ASHA NOMS stratified by clinical history of ALS.

Discussion

Key Results

Oropharyngeal dysphagia is an important symptom of ALS that directly compromises the quality of life of the patients. We conducted this study to observe the time progression of OD in patients affected by ALS.

Our demographic data described in Table 1 were similar to the epidemiological data present in the literature, more specifically, the percentage between spinal (2/3) and bulbar (1/3) onset types. The higher incidence in older age groups, reflected by the mean age of 68 years in our study, as well as the higher prevalence in women in the bulbar-onset group, well agreed with the study of Chiò et al.[3]

By the end of our study, 71.9% of the sample (23 subjects) had been recommended PEG placement. Out of these, 69.6% had emerging symptoms of the spinal disease, as already observed in literature by Plowman et al. in 2017.[23]

Our results also suggest that the progression of dysphagia in ALS is not regular, and slowdown phases can be highlighted, as reflected in Figure 1.

Our data are consistent with the previous study of Shoij et al.,[8] who examined the natural course of dysphagia in ALS. Notably, we should underline that, despite the presence of OD as a symptom of onset of bulbar ALS, it tends to progress more slowly when compared with OD which appears in spinal ALS.

This result was in line with the 2017 research of Onesti who postulated that at the beginning of the disease, dysphagia was more frequently prevalent in patients with bulbar onset variety, but the duration of the disease in spinal patients influenced frequency of dysphagia.[24]

Limitations and Strength

Cross-sectional studies do not establish a clear cause-and-effect relationship between exposure and disease, nor do they ensure high-quality data on exposure. These studies tend to include prevalent cases rather than incident ones, which makes them prone to biases that are difficult to eliminate. Despite these limitations, prevalence data remain crucial in public health for understanding the burden of disease in specific populations and for guiding the allocation of healthcare resources. This study aimed to explore whether there is a difference in the progression of OD between the two main forms of ALS.

Interpretation

Current research does not fully clarify the location of potential sensory impairments in the pathway of tussigenic stimuli, including peripheral airway sensory receptors, brainstem CPG, subcortical thalamic filtering, and higher cortical processing, all of which contribute to somatosensory responses.[24] Although ALS is primarily associated with motor dysfunction, these findings suggest that sensory degradation in the upper airways could affect reflexive motor responses to airway invasion.

Moreover, it is known that the larynx has only one abductor muscle, the posterior cricoarytenoid, and several smaller intrinsic adductor muscles. These intrinsic laryngeal muscles interact in complex ways during functions such as coughing, speaking, and swallowing, typically acting together. In particular, stimulation of highly sensitive receptors in the supra-glottic larynx triggers reflexes that protect the airways from foreign bodies. However, these reflexes may become disrupted in ALS patients. As Tomik noted, dysfunction of the vagus nerve can occur early in patients with spinal ALS, even before clinical signs of bulbar dysfunction appear.[25]

In our observation, while speech therapy for dysphagia did not alter the progression of the symptom, it enabled patients and caregivers to adopt compensatory postures and modify food consistencies during meals.

Standard ALS care does not provide specific guidelines on the timing or methods of dysphagia assessment. There is limited evidence supporting particular recommendations, and many questions remain, such as the role and timing of instrumental evaluations in assessing dysphagia in ALS. Our findings emphasize the value of regular clinical and instrumental assessments, such as FEES, conducted every 4–6 months. Additionally, a multidisciplinary approach, involving at least a neurologist, otolaryngologist, respiratory therapist, SLP, occupational therapist, and nutritionist, can significantly aid patients and their families. This team can work together to improve patients' quality of life and potentially extend survival. Such an approach ensures comprehensive and interdisciplinary care throughout the various stages of ALS.

This model could serve as the foundation for creating an individualized care program that includes: (1) ongoing evaluation and monitoring of swallowing function, (2) nutritional education and food modification, and (3) screening and agreement on the appropriate timing for enteral nutrition.

In conclusion, our study demonstrated variability in the progression of OD among ALS patients. By regularly monitoring patients with FEES and collaborating with a multidisciplinary team, it is possible to help preserve oral feeding and improve quality of life. Furthermore, this approach could reduce the risk of aspiration pneumonia, and PEG tube placement can be considered based on the patient's residual swallowing function and nutritional status.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Disclosure of Ethical Statements

This study was approved by our Ethical Committee (Prot. 1976/CEL) and IRCCS Istituto Oncologico "Giovanni Paolo II" Bari, Italy.
Approval of the research protocol: Prot. 1976/CEL.
Registry and the Registration No. of the study/trial: (Prot. 1976/CEL).

Authors Contributions

Alessandro De Stefano: Conceptualization, Investigation, Methodology, Writing Original Draft, writing Review and editing, Project Administration. Antonino Greco: Investigation, Writing original draft. Francesco Gattulli: Investigation. Antonio Merico: Investigation. Pamela Di Giovanni: Formal analysis. Gautham Kulamarva: Investigation, writing review and editing. Francesco Dispenza: Data curation. Oliviero Capparella: Approved the final version of the study.

All authors reviewed and approved the final version of the manuscript. All authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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