Esclerose Lateral Amiotrófica

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CoDAS
ISSN 2317-1782 (Online version)

Relato de Caso
Case Report

Cuidados paliativos, esclerose lateral amiotrófica e deglutição: estudo de caso

Palliative care, amyotrophic lateral sclerosis, and swallowing: a case study

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Descritores

Cuidados Paliativos
Deglutição
Esclerose Lateral Amiotrófica
Qualidade de Vida
Fonoaudiologia
Disfagia

RESUMO

Tem-se por objetivo discutir aspectos da atuação fonoaudiológica em disfagia, voltada para os cuidados paliativos e a qualidade de vida em deglutição. Trata-se de um estudo de quatro casos com esclerose lateral amiotrófica (ELA) em acompanhamento fonoaudiológico. Foi aplicado o questionário de qualidade de vida em disfagia (SWAL-QOL), realizada entrevista estruturada, classificação da funcionalidade da deglutição pela *Funcional Oral Intake Scale* (FOIS), aplicação da escala de gravidade da ELA (EGELA), realizada videofluoroscopia da deglutição e classificação da severidade da disfagia pela *Dysphagia Outcome Severity Scale* (DOSS). Observou-se que os casos apresentavam tempo de doença entre 12 e 35 meses e possuíam o desejo de manter uma via oral de alimentação, mesmo que mínima, em caso de aceitação da via alternativa de alimentação. Quanto à severidade da disfagia, observada por meio do exame de videofluoroscopia e classificada pela DOSS, apresentavam desde deglutição funcional até disfagia leve a moderada. O impacto na qualidade de vida em deglutição foi mensurado entre discreto e severo. Nem todos apresentavam correspondência entre a severidade da disfagia e a qualidade de vida em deglutição, sendo observado impacto na qualidade de vida, mesmo nos casos com menor grau de disfagia. Os participantes relataram que se sentiriam desconfortáveis em caso de alimentação exclusiva por via alternativa e que a ingestão de alimentos por via oral, mesmo que mínima, apenas pelo prazer da alimentação, refletiria em sua qualidade de vida.

Practice Guideline > Muscle Nerve, 59 (5), 531-536 May 2019

Provisional Best Practices Guidelines for the Evaluation of Bulbar Dysfunction in Amyotrophic Lateral Sclerosis

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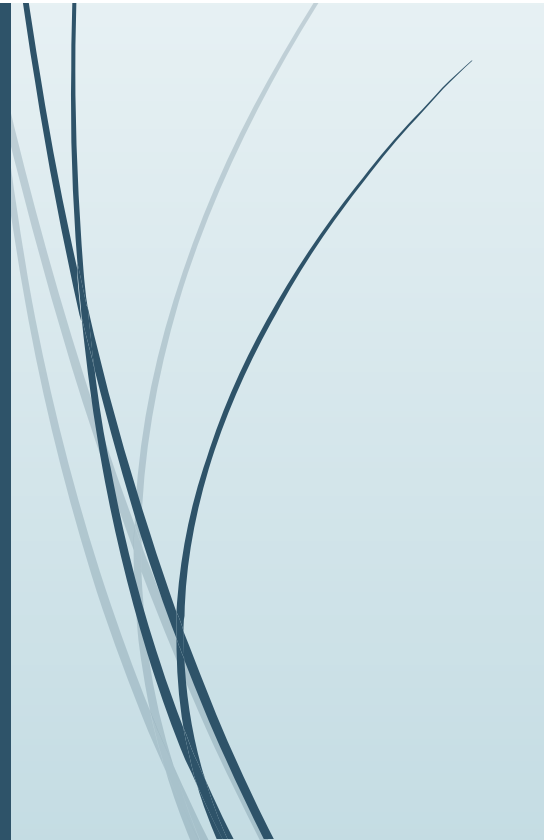
PMID: 30620104 DOI: 10.1002/mus.26408



Abstract

Introduction: Universally established comprehensive clinical bulbar scales objectively assessing disease progression in amyotrophic lateral sclerosis (ALS) are currently lacking. The goal of this working group project is to design a best practice set of provisional bulbar ALS guidelines, available for immediate implementation within all ALS clinics.

Methods: ALS specialists across multiple related disciplines participated in a series of clinical bulbar symposia, intending to identify and summarize the currently accepted best practices for the assessment and management of bulbar dysfunction in ALS Results: Summary group recommendations for individual speech, Augmentative and Alternative Communication (AAC), and swallowing sections were achieved, focusing on the optimal proposed level of care within each domain.

Discussion: We have identified specific clinical recommendations for each of the 3 domains of bulbar functioning, available for incorporation within all ALS clinics. Future directions will be to establish a formal set of bulbar guidelines through a methodological and evidence-based approach. Muscle Nerve 59:531-531, 2019.

Keywords: AAC; Bulbar; Guidelines; Speech; Swallowing.

Published in final edited form as:
Amyotroph Lateral Scler Frontotemporal Degener. 2017 August ; 18(5-6): 351–357. doi: 10.1080/21678421.2017.1313868.

The Evaluation of Bulbar Dysfunction in Amyotrophic Lateral Sclerosis: Survey of Clinical Practice Patterns in the United States

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Abstract

Objective: Speech and Swallowing impairments are highly prevalent in individuals with amyotrophic lateral sclerosis (ALS) and contribute to reduced quality of life, malnutrition, aspiration, pneumonia and death. Established practice parameters for bulbar dysfunction in ALS do not currently exist. The aim of this study was to identify current practice patterns for the evaluation of speech and swallowing function within participating Northeast ALS clinics in the United States.

Methods & Results: A 15-item survey was emailed to all registered NEALS centers. Thirty-eight sites completed the survey. The majority (92%) offered Speech-Language Pathology, augmentative and alternative communication (71%), and dietician (92%) health care services. The ALS functional rating scale-revised and body weight represented the only parameters routinely collected in greater then 90% of responding sites. Referral for modified barium swallow study was routinely utilized in only 27% of sites and the use of percutaneous gastrostomy tubes in ALS patient care was found to vary considerably.

Conclusions: This survey reveals significant variability and inconsistency in the management of bulbar dysfunction in ALS across NEALS sites. We conclude that a great need exists for the development of bulbar practice guidelines in ALS clinical care to accurately detect and monitor bulbar dysfunction.

Keywords

amyotrophic lateral sclerosis; bulbar; practice patterns; speech; swallow; survey

Summary of Question 10 short answer responses (n=18).

Rationale for not performing a Modified Barium Swallowing Study
Physician preference only.
SLP and physician clinical assessments are sufficient.
MBS poses the risk for barium aspiration.
The disease progresses too quickly for MBS to be useful.
It does not add useful information.
Clients often seen for an MBS during differential diagnosis prior to being referred to our clinic.
We refer only a small number of patients who want to remain eating (and defer PEG tube placement) to enhance and educate on safe swallowing techniques.
No access to MBS on-site.
MBS does not provide education and treatment recommendations to make it worthwhile.
The SLP (seen outside of our clinic) will usually send for this.
We go by patient report of symptoms.
Taught in fellowship MBS not necessary since dysphagia is expected and results don't change management.
If they report choking episodes associated with weight loss, we refer for a feeding tube.

Arch Bronconeumol. (2013);49(12):529–533

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Special Article

Comprehensive Care of Amyotrophic Lateral Sclerosis Patients: A Care Model☆

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ARTICLE INFO

Article history:
Received 23 October 2012
Accepted 28 January 2013
Available online 28 October 2013

Keywords:
Amyotrophic lateral sclerosis
Interdisciplinary team
Care model
Home nursing team
Home mechanical ventilation
In-Exsufflator
Tracheostomy
Percutaneous gastrostomy

ABSTRACT

Amyotrophic lateral sclerosis (ALS) is a devastating neurodegenerative disease that presents with muscle weakness, causing progressive difficulty in movement, communication, eating and ultimately, breathing, creating a growing dependence on family members and other carers. The ideal way to address the problems associated with the disease, and the decisions that must be taken, is through multidisciplinary teams. The key objectives of these teams are to optimise medical care, facilitate communication between team members, and thus to improve the quality of care. In our centre, we have extensive experience in the care of patients with ALS through an interdisciplinary team whose aim is to ensure proper patient care from the hospital to the home setting. In this article, we describe the components of the team, their roles and our way of working.

Table 1
Team Members and Their Duties.

Team member	Specific duties
Neurologist	- Direction of the disease diagnostic process - Communication of the diagnosis and therapeutic options - Monitoring of the neurological evolution - Prescription of aetiopathogenic and symptomatic treatment - Direct responsibility during admissions to the Neurology ward - Final responsibility for consensual decisions with the patient
Pulmonologist	- Respiratory evaluation and monitoring - Prescription and monitoring of specific treatments (DCO, HMV, Cough Assist) - Direct responsibility in patient admission for HMV adaptation/other therapies - Change of tracheostomy cannulae
Rehabilitation physician	- Functional and therapeutic needs assessment - Instrumental assessment of swallowing - Control of salivation (instillation of Botox, drugs, etc.) - Orthopaedic assessment and prescription
Respiratory physiotherapist	- Education, adaptation and monitoring of the patient with HMV - Respiratory and general physiotherapy - Link with out-of-hospital rehabilitation teams
Speech therapist	- Clinical evaluation of speech and swallowing disorders - Rehabilitative treatment of speech and swallowing disorders - Guidelines and advice in relation to communication systems
Hospital respiratory nurse	- Education and nursing care of the patient - Performing lung function tests in situ - Assisting in changing tracheotomy tubes
Dietitian/nutritionist	- Evaluation and monitoring of the nutritional status - Adaptation of food to energy-nutritional requirements - Prescription of oral nutritional supplements - Prescription and monitoring of home enteral nutrition
Home nursing team	- Optimisation of the efficacy and comfort of HMV and other treatments. Education - Identification and assessment of the problems of the patient and their family in the home - Change of tracheostomy cannulae or PG - Adaptation to home NIV and mechanical secretion clearance systems - Coordination and collaboration with external support teams in patient care
Social worker	- Evaluation of the patient's social situation and environment - Orientation and treatment of social problems

HCO, home continuous oxygen therapy; HMV, home mechanical ventilation; NIV, non-invasive ventilation; PG, gastrostomy tube.