

Karen Fontes Luchesi¹
Satoshi Kitamura²
Lucia Figueiredo Mourão²

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Correspondence address:

Karen Fontes Luchesi
Centro de Estudos e Pesquisas em
Reabilitação (CEPRE/FCM/UNICAMP)
Av. Tessália Vieira de Camargo,
126, Cidade Universitária, Campinas
(SP), Brazil, CEP: 13083-887.
E-mail: karenluchesi@yahoo.com.br

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Management of dysphagia in Parkinson's disease and amyotrophic lateral sclerosis

Gerenciamento da disfagia na doença de Parkinson e na esclerose lateral amiotrófica

ABSTRACT

Purpose: To describe swallowing management in patients with amyotrophic lateral sclerosis (ALS) and Parkinson' disease (PD), to investigate whether physiopathology determines the choice of therapeutic approaches, and to investigate whether the disease duration modifies the therapeutic approaches. **Methods:** This is a long-term study comprising 24 patients with idiopathic PD and 27 patients with ALS. The patients were followed-up in a dysphagia outpatient clinic between 2006 and 2011. The patients underwent clinic evaluation and Fiberoptic Endoscopic Evaluation of Swallowing, Functional Oral Intake Scale, and therapeutic intervention every 3 months. The swallowing management was based on orientation about the adequate food consistency and volume, besides the necessary maneuvers or exercises to improve swallowing functionality. An exploratory analysis of data was used to investigate associations between the groups of disease (PD or ALS) and clinic aspects and to know about the association between the groups of diseases and the application of maneuver or exercises over the follow-up. **Results:** The most frequent recommended maneuvers in PD were bolus effect (83.3%), bolus consistency (79.2%), and swallowing frequency (79%). To patients with ALS, the bolus consistency (92%) and the bolus effect (74.1%) were more recommended. Strengthening-tongue (p=0.01), tongue control (p=0.05), and vocal exercises (p<0.001) were significantly more recommended in PD than in ALS. **Conclusion:** Compensatory and sensorial maneuvers are more recommended to rehabilitee program in both diseases. The physiopathology of the diseases determined the choice of therapeutic approaches. The disease duration of the patients did not interfere directly in the therapeutic approaches.

RESUMO

Objetivo: Descrever o gerenciamento da disfagia na doença de Parkinson (DP) e na Esclerose Amiotrófica Lateral (ELA) e verificar se as características fisiopatológicas das doenças determinam a escolha das abordagens terapêuticas para disfagia, além de investigar se a duração da doença modifica estas abordagens. **Métodos:** Trata-se de um estudo longitudinal com 24 pacientes diagnosticados com DP e 27 pacientes com ELA. Os pacientes foram acompanhados em um ambulatório de disfagia entre os anos de 2006 e 2011. Todos foram submetidos à avaliação clínica e nasofibrocópica de deglutição, classificação pela *Functional Oral Intake Scale* e intervenção terapêutica a cada três meses. O programa de gerenciamento da disfagia baseou-se na orientação sobre a adequada consistência e volume para alimentação, além de manobras ou exercícios necessários para melhorar a funcionalidade da deglutição. Foi utilizada uma análise exploratória dos dados para investigar a associação entre os grupos de doença (DP ou ELA) e aspectos clínicos, além de verificar associação entre os grupos de doenças e a indicação das manobras e exercícios em um seguimento longitudinal. **Resultados:** As manobras e estratégias mais indicadas para DP foram: modificações quanto às características do bolo alimentar (83,3%), modificações na consistência do bolo alimentar (79,2%) e deglutições múltiplas (79%). Para ELA, as mais indicadas foram modificações na consistência (92%) e nas características do bolo alimentar (74,1%). Em comparação com a ELA, para DP foram mais indicados exercícios para força e controle de língua (p=0,01 e 0,05) e exercícios vocais (p<0,001). **Conclusão:** As manobras compensatórias e sensoriais são as mais indicadas em ambas as doenças. As características fisiopatológicas das doenças determinaram a escolha das abordagens terapêuticas. O tempo de doença dos pacientes não interfere diretamente nas abordagens terapêuticas.

Study carried out at the Universidade Estadual de Campinas – UNICAMP – Campinas (SP), Brazil.

(1) Universidade Estadual de Campinas – UNICAMP – Campinas (SP), Brazil.

(2) School of Medicine at the Universidade Estadual de Campinas – UNICAMP – Campinas (SP), Brazil.

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INTRODUCTION

Dysphagia is a disorder that compromises one or more stages of swallowing. It is usually a symptom of some underlying disease and manifests itself as coughing and choking during or after a meal, chewing difficulty, drooling, weight loss, and aspiration pneumonia⁽¹⁾. It is a frequent counterpart of neurological disorders, especially those with prominent motor dysfunction.

Amyotrophic lateral sclerosis (ALS) and Parkinson's disease (PD) are neurodegenerative diseases that will course with dysphagia and have its complications (such as malnutrition and aspiration pneumonia) as the major causes of death^(2,3).

Dysphagia in PD is very common and affects more than 80% of individuals, reflecting the underlying motor impairments and the extent of the disease progression⁽⁴⁾. The swallowing difficulties most frequently associated with PD are related to the oral and pharyngeal phase, resulting in abnormal bolus formation, multiple tongue elevations, delayed swallowing reflex, and prolongation of the pharyngeal transit time with repetitive swallows to clear the throat⁽⁵⁾.

Dysphagia in patients with ALS is associated with atrophy and dyskinesia of the tongue, caused by nuclear or supranuclear lesion of the hypoglossus, vagus, and glossopharyngeal nerves. It leads to failure in the closure of the soft palate, nasal reflux, and change in larynx closure, reducing airway protection⁽⁶⁾.

The physiopathology and etiology of dysphagia are different in these diseases. PD is characterized by impairment of basal ganglia. PD reduces voluntary movements and causes resting tremor, rigidity, akinesia (or bradykinesia), and postural instability^(7,8). ALS is characterized by progressive degeneration of lower and upper-motor neurons in the cerebral cortex, brainstem, and spinal cord. ALS results in muscular atrophy, fasciculation, weakness, and spasticity⁽⁹⁾.

Dysphagia is an important symptom in the prognosis of ALS and PD. Correct diagnosis, appropriate therapeutic interventions, and management of swallowing are very necessary⁽¹⁰⁾. At the moment, there are few publications describing swallowing management programs (SMPs) and its swallowing maneuvers or exercises.

Swallowing management, through the utilization of methods that compensate for the alterations in the swallowing process, aims to preserve a safe oral feeding as long as possible. ALS and PD are two of the most common neurodegenerative diseases in SMP.

The maneuvers used in swallowing managements can be categorized by their objectives and characteristics. Robbins et al.¹¹ describe the first category as "compensatory," with the maneuvers of chin-tuck, head rotation, head tilt, head back, side-lying, bolus consistency, and breath holding. The "motor without swallow" category includes range of motion, strengthening-tongue, strengthening-respiratory, tongue control, shaker, Lee Silverman Voice Treatment (LSVT), pharyngeal exercise, gargling, vocal exercises, velar elevation, and airway closure/breath holding. The "motor with swallow" category includes Mendelsohn, super supraglottic, supraglottic, effortful, tongue holding, and swallow (frequency). The "sensorial" category includes bolus effects (volume, viscosity, temperature, and

taste enhancement) and stimulation (thermal-tactile stimulation, electrical stimulation, occluding tract, and visual feedback).

Few studies describe the therapeutic intervention in the management of dysphagic patients with neurodegenerative disease. This study raises some hypothesis that may interfere in therapeutic choices such as: (i) the physiopathology of the disease determines the choice of therapeutic approaches and (ii) the disease duration influences the therapeutic approaches. This article aims to test these hypotheses in a case series of patients with ALS and PD.

METHODS

This study was approved by the Ethic Board Committee of the Faculty of Medical Sciences at the University of Campinas, Brazil (Protocol Number 796/2005). There was no need for a consent form because this study had secondary access to the data.

Selection of patients

It is a long-term study that included 51 patients. They were divided into two groups: group 1, 24 patients with idiopathic PD, and group 2, 27 patients with ALS. The patients were regularly followed-up at a dysphagia outpatient clinic, in a large Brazilian university hospital, in a 5-year period (2006–2011). It was an open case series, and during the 5 years of study there were patients moving in and out.

Only patients who had at least two evaluations, complaints of swallowing, no prior nonoral feeding, and regular check-ups with Outpatient Neurology were included in the study. Patients with concomitant disorders able to cause dysphagia were excluded from the analysis. ALS patients with frontotemporal involvement were also excluded.

Procedures

Every procedure was conducted based on a published protocol of swallowing evaluation⁽¹²⁾.

The patients underwent swallowing evaluation, functional oral intake scale (FOIS), and therapeutic intervention every 3 months.

The swallowing evaluation was obtained through a Fiberoptic Endoscopic Evaluation of Swallowing (FEES) and clinical evaluation. In both evaluations, the following types of food were offered: (i) lemon juice colored with green dye; (ii) nectar, honey, and pudding consistencies, all colored with green dye [these fluids were obtained with the addition of two, three, and four teaspoons of a thickener (Thicken-easy[®]) to 100 mL of water, respectively, and were offered in two different quantities, 3 mL and 7 mL]; (iii) a solid consistency was represented by a cornstarch biscuit.

The food was given to patients in the following sequence: liquid and nectar (3, 3, 7, and 7 mL); honey (3, 3, 7, and 7 mL); pudding (2 tablespoons); and solid (½ cornstarch biscuit). The liquid, nectar, and honey consistencies were administered in 20 mL syringes, with the sample introduced into the patient's

oral cavity. As difficulties in swallowing were observed, protective maneuvers of the airways and/or changes in head posture were performed in order to assist oral feeding in a safe way.

FEES were carried out by an otolaryngologist while the food was offered by a speech-language therapist.

In the clinical evaluation, as the patients swallowed, cervical auscultation was performed to identify abnormal signs at the pharyngeal swallowing phase. Oral bolus transit time, anterior or posterior escape, positive cervical auscultation (with signs that indicate a presence of stasis or penetration with aspiration risk), coughing (before, during, or after swallowing), and wet voice were also observed.

Based on the clinical evaluation and FEES, the FOIS¹³ was applied. The FOIS ranks patients into levels. For the present study, the levels are described as follows: level 1, nothing by mouth; level 2, tube dependent with minimal attempts of food or liquid; level 3, tube dependent with consistent oral intake of food or liquid; level 4, total oral diet of one or two consistencies (nectar and honey, honey and pudding); level 5a, total oral diet with multiple consistencies but with restriction of two consistencies (e.g., solid and liquid), with or without compensation; level 5b, total oral diet with multiple consistencies but with restriction of one consistency (e.g., solid or liquid), with or without compensation; level 5c, total oral diet with multiple consistencies, but requiring compensation; level 6, total oral diet with multiple consistencies without special preparation but with specific food limitations (e.g., fibers, grains, and some vegetables) and speed and volume modification if necessary; level 7, total oral diet with no restriction.

At the initial evaluation, every patient received an FOIS classification. To analyze the changes in swallowing functionality, the difference in the initial and final FOIS level of every patient was observed. The changes in these two measures were calculated and expressed in the variable “Changing levels of FOIS.”

This article does not aim to discuss the results of FEES; it was described only to clarify to the readers the process of swallowing evaluation, upon which the intervention was based.

Following these swallowing evaluations, every 3 months, patients received therapeutic intervention regarding adequate food consistency and volume, besides maneuvers or exercises to improve swallowing functionality. They were oriented to perform the maneuvers or exercises daily and received written instructions for each one.

In the “compensatory” category, the maneuvers used were chin-tuck to improve airway protection during swallowing and bolus consistency to facilitate the feeding of patients with decreased coordination of tongue, reduced contraction of pharynx, delay in triggering swallowing reflex, reduced airway protection, and chewing difficulty.

In the “motor without swallow act” category, the following were used: (i) strengthening-tongue to improve bolus propulsion; (ii) tongue control to improve tongue mobility and facilitate the bolus management in the oral cavity; (iii) shaker to increase strength in supra hyoid muscles, reducing the penetration and aspiration risk due to stasis in pyriform sinus;

(iv) vocal exercises to improve airway protection through the improvement in the glottis adduction.

In the “motor with swallow act” category, the following were used: (i) effortful swallow to increase strength to eject the bolus and to approximate the larynx structures, improving airway protection; (ii) tongue holding (Masako maneuver) to increase movements of pharyngeal muscles against the basis of the tongue during the act of swallowing; (iii) frequency of swallowing (multiple swallows) to clear stasis.

The “sensorial” category includes bolus effects (changes in volume, viscosity, temperature, or taste in order) to improve oral and pharyngeal sensibility and control bolus management.

Data analyses

Descriptive analysis was performed for the frequency of categorical variables and median measures and standard deviation for numeric variables.

In order to investigate the differences between the groups of disease (PD or ALS) and clinic aspects (such as age at onset of the disease, age at the first evaluation, time of follow-up, and changing levels of FOIS), Mann–Whitney test was used.

To study the relation between the indication of maneuvers and disease duration (disease duration=time between the onset of disease symptoms and the first evaluation) or groups of disease, Mann-Whitney and chi-square tests were used.

The statistical analysis was performed using the Statistical Package for the Social Sciences software version 13.0 for Windows, and *p*-values lower than 0.05 were considered significant.

RESULTS

The groups of patients had similar age at first clinic visit, they were similar about gender, but had significant difference about age at onset of symptoms ($p=0.004$), disease duration ($p=0.001$), time of follow-up ($p=0.002$), and changing levels of FOIS ($p=0.001$). Table 1 summarizes the descriptive and exploratory analyses of these variables.

Due to the fact that this study was based on an open case series and during the 5 years of study there were patients moving in and out, they were followed-up by different periods. Figures 1 and 2 show the period of follow-up of every patient. The majority of ALS patients were followed-up for 15 months and the PD patients for a median of 29.5 months.

Figures 3 and 4 show the changing levels of FOIS during the follow-up. The difference between the two groups of patients is remarkable. In ALS patients, the swallowing functionality only worsened. It worsened by a median of 2.5 levels of FOIS during the period of follow-up. In PD patients, the swallowing functionality even improved. These patients had a positive changing level of FOIS; it improved by a median of 2.5 levels.

Table 2 summarizes the frequency of recommendation of maneuvers over the follow-up. The most indicated maneuvers in both groups were chin-tuck, bolus effect, bolus consistency, and multiple swallows.

About the peculiarities of the dysphagia management in the two groups, it was observed that comparing ALS with

PD, strengthening-tongue (p=0.01), tongue control (p=0.05), and vocal exercises (p<0.001) were significantly more recommended in the PD group. The maneuvers and exercises of the categories motor without swallowing act and motor with swallowing act were more recommended for the PD group (p=0.04 and 0.003, respectively).

DISCUSSION

The differences between the groups were expected and showed the representativeness of the studied sample. Both diseases cause an oropharyngeal dysphagia, but due to the difference in disease progression, a significant disproportion in disease

Table 1. Descriptive and exploratory analyses of variables: gender, age at first evaluation, age at onset of symptoms, time of follow-up, disease duration, and changing levels of functional oral intake scale comparing a case series of amyotrophic lateral sclerosis (n=27) and Parkinson disease (n=24) Brazilian patients followed between 2006 and 2011

Variables	Amyotrophic lateral sclerosis			Parkinson's disease			p-value
	Min-Max	Mean±SD	Median	Min-Max	Mean±SD	Median	
Gender (male/female)		12/15			16/8		0.30
Age at first evaluation (years)	37-73	55.3±10.3	56.0	51-81	64.7±9.4	64	0.004**
Age at onset (years)	36-71	53.0±10.2	54.5	39-55	57.0±10.0	53	0.33
Follow-up (months)	6-65	18.6±13.6	15.0	7-67	32.0±16.7	29.5	0.002
Disease duration (months)	12-96	27.7±20.5	24	24-204	93.5±57.8	78	<0.001**
Changing levels of functional oral intake scale*	0 to -6	-2.3±1.9	-2.5	1 to -6	2.3±2.0	2.5	0.001**

*The positive numbers indicate improvement, the negative ones indicate worsening, and zero indicates no change in swallowing functionality.
 **Significant values.

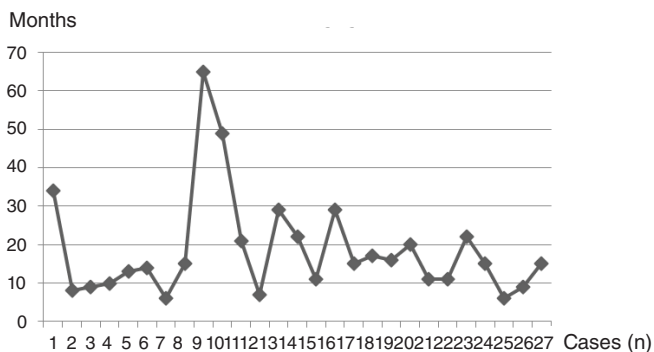


Figure 1. Number of amyotrophic lateral sclerosis patients in follow-up in a dysphagia outpatient clinic between 2006 and 2011 (n=27)

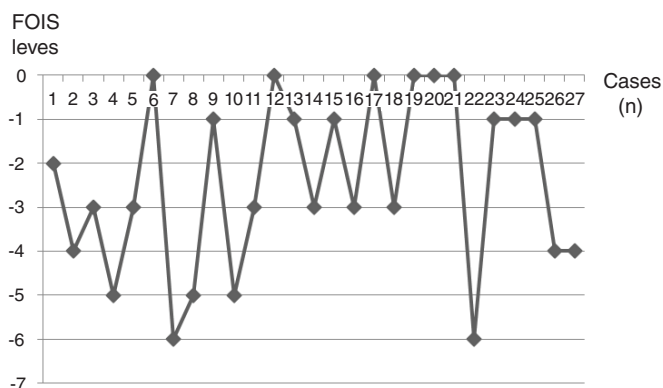


Figure 3. Changing levels of functional oral intake scale in amyotrophic lateral sclerosis patients during follow-up in a dysphagia outpatient clinic between 2006 and 2011 (n=27)

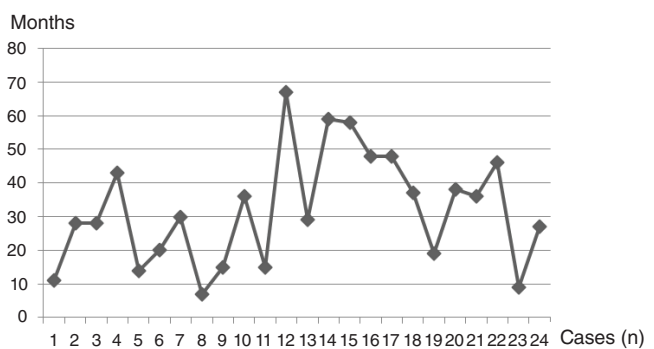


Figure 2. Number of Parkinson disease patients in follow-up in a dysphagia outpatient clinic between 2006 and 2011 (n=27)

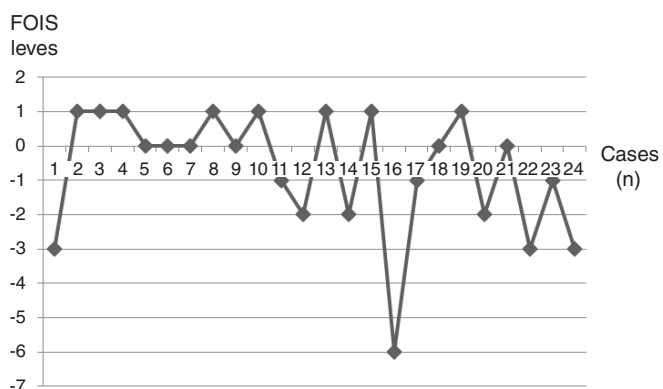


Figure 4. Changing levels of functional oral intake scale in Parkinson disease patients during follow-up in a dysphagia outpatient clinic between 2006 and 2011 (n=27)

Table 2. Frequency of maneuvers recommended in swallowing management and its level of statistic association with Parkinson' disease and amyotrophic lateral sclerosis, in a case series of Brazilian patient with amyotrophic lateral sclerosis (n=27) and Parkinson' disease (n=24) followed-up in a dysphagia outpatient clinic between 2006 and 2011

Method	Maneuvers	Parkinson' disease n (%)	Amyotrophic lateral sclerosis n (%)	p-value
Compensatory	Chin-tuck	16 (66.7)	13 (48.1)	0.14
	Head rotation	1 (4.2)	0	0.47
	Head tilt	0	0	–
	Head back	0	0	–
	Side lying	0	0	–
	Bolus consistency	19 (79.2)	25 (92.6)	0.16
	Breath holding	0	0	–
Motor without swallow act	Strengthening-tongue	16 (66.7)	8 (29.6)	0.009*
	Tongue control	10 (41.7)	4 (14.8)	0.03*
	Strengthening-respiratory	0	0	–
	Shaker	3 (12.5)	1 (3.7)	0.26
	Lee Silverman Voice Treatment	0	0	–
	Pharyngeal exercise	0	0	–
	Gargling	0	0	–
	Vocal exercises	12 (50.0)	1 (3.7)	<0.001*
Motor with swallow act	Velar elevation	0	0	–
	Airway closure/breath holding	0	0	–
	Mendelssohn	0	0	–
	Supraglottic	1 (4.2)	0	0.47
	Super supraglottic	0	0	–
	Effortful	10 (41.7)	14 (51.9)	0.32
	Tongue holding	4 (16.7)	1 (3.7)	0.14
Sensorial	Swallow frequency (multiple swallows)	19 (79.2)	14 (51.9)	0.04*
	Bolus effects	20 (83.3)	20 (74.1)	0.16
	Stimulation	0	3 (11.1)	0.14

*Significant values

duration and changing levels of FOIS were observed in this study. Longer disease duration and smaller changing in swallowing functionality in PD than in ALS patients were observed.

The differences between the studied groups were due to the discrepancies, impairment, and evolution of the two diseases. According to literature, the onset of ALS symptoms is expected to occur in patients around 55–65 years old. These patients usually have a life expectancy between 2 and 5 years after symptom onset⁽¹⁴⁾. In this study, the PD group had an older onset of symptoms, a longer disease duration, and consequently a longer time of follow-up with fewer changing in swallowing functionality, according to FOIS. The literature registers a PD onset in patients around 65 years old and an average disease duration of 8.8 years⁽¹⁵⁾.

Despite the physiopathology difference, compensatory and sensorial maneuvers such as chin-tuck, bolus consistency, bolus effect, and multiple swallowing were frequently recommended to both groups.

The recommendation of chin-tuck and multiple swallowing during the daily feeding aimed to improve airway protection, reducing the chance of larynx penetration or aspiration.

Bolus consistency was indicated when other maneuvers were inefficient to maintain complete oral feeding and was necessary to avoid the consistencies that were hazardous to the

patient. It was recommended the bolus effect when the lack of oral sensibility or oral control turned hard swallowed quickly and in greater volume.

There were peculiarities in dysphagia management in the two groups. It was observed that for the PD group, maneuvers of the categories motor with and without swallowing act such as strengthening-tongue, tongue control, and vocal exercises were significantly more indicated.

Swallowing management in Parkinson' disease

This SMP aimed to improve swallowing act as possible and to introduce compensations in order to save a feeding. Two of the most recommended maneuvers were head position change (chin-tuck) and changing in bolus consistency. Literature showed evidences that in PD patients the chin-tuck maneuver combined with thick liquid can be important to prevent pneumonia⁽¹⁶⁾.

The vocal exercises, which were significantly more recommended for PD patients compared with ALS patients, can improve the cough function and tongue mobility during the swallowing⁽¹⁷⁾.

According to the literature, such as the results of this article, in the PD group, compensatory interventions are usually

recommended. These interventions were designed to redirect the bolus away from the airway. Thickening liquids to a nectar or honey consistency are generally used and exhibit an immediate effect⁽¹⁸⁾.

Exercises for tongue strengthening (exercises aiming at propulsion of bolus) and control were frequently recommended due to tongue movements of PD patients, especially those responsible for propulsion and chewing are considered hypokinetic in the oral phase. Consequently, oral swallowing phase is usually longer and even slower than pharyngeal phase⁽¹⁹⁾.

Another frequently recommended maneuver for PD patients was the effortful swallow. The effectiveness of these maneuvers was confirmed by another Brazilian study⁽²⁰⁾. It improves the bolus propulsion and approaches the larynx cartilages, increasing airway protection. This maneuver was designed to improve the posterior movement of the base of the tongue, which is stiff and slowed in PD patients, and prevent the accumulation of stasis in the vallecula.

Swallowing management in amyotrophic lateral sclerosis

Unlike PD, in ALS the muscle fatigue is prevalent and exercises for tongue's control and tongue's strength, even necessary, are not indicated. Fatigue or loss of resistance is a frequent complaint among patients with ALS⁽²¹⁾.

Due to the nonindication of exercises to improve tongue's stretch, this SMP recommended compensatory and sensorial strategies for ALS patients. As the literature suggested, modification of food consistency (blending solid and thickening liquids), postural changes, and effortful swallowing were recommended⁽²²⁾. In ALS, the weakness and muscle paralysis that also affect the efficiency of propulsion of the bolus can cause larynx stasis and consequently larynx penetration and aspiration. Despite the muscle fatigue, in this SMP, the maneuver of effortful swallowing was recommended, considering it is a maneuver performed during the swallowing function and does not demand a muscle strength such as an isolated exercise. Its importance was empirically observed and showed effectiveness for bolus propulsion and airway protection.

An Italian study observed the chin-tuck maneuver as an effective maneuver in cases of preswallowing aspiration, generally resulting from abnormalities of the oral phase⁽²³⁾. This maneuver offers an important protection mechanism for the airway. It opens the vallecula. In this position, the base of the tongue narrows and covers the larynx opening and consequently prevents penetration and aspiration.

The literature showed that patients treated from early stages of ALS can develop muscle adaptive mechanisms and reduce the risk of aspiration⁽²⁴⁾.

Speech therapy interventions for ALS patients are strongly suggested. While oral feeding is possible, maneuvers such as bolus consistency and bolus effect (alterations in the consistency, amount, taste, or temperatures of foods), effortful swallowing, and chin-tuck can improve oral intake and prevent aspiration. The chin-tuck position is frequently recommended for swallowing of liquids and effortful swallowing at all meals⁽²⁴⁾.

Due to the presence of muscle fatigue, the recommendation of fractionating meals is also important.

In ALS, it is necessary to maintain safe oral feeding for as long as possible, but not unduly postpone nonoral feeding. It is important to recommend nonoral feeding when the patient lacks the ability to swallow safely or cannot maintain the body nutrition exclusively by oral feeding due to any other reason. A delay in the introduction of nonoral feeding can result in complications such as the previously mentioned aspiration pneumonia, malnutrition, and, ultimately, death.

CONCLUSION

ALS and PD are neurodegenerative progressive diseases that affect the swallowing functionality during their evolution. SMPs aim to maintain safe oral feeding for as long as possible.

An association between the diseases and recommendation of maneuvers and exercises are observed, but in this sample, the disease duration did not interfere directly in the choice of therapeutic methods.

Physiopathology of the disease determined the choice of therapeutic approaches. In PD, strengthening-tongue, tongue control, and vocal exercises were significantly more recommended. In ALS, bolus consistency and bolus effect were frequently recommended.

The most indicated maneuvers in both diseases were chin-tuck, bolus effect, bolus consistency, and multiple swallows.

**KFL was responsible for collecting, tabulating and analyze data, besides manuscript preparation; SK and LFM were responsables for the study design and general orientation of stages of execution and manuscript preparation.*

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