

Quality of life in patients with neurogenic dysphagia

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Introduction: *Dysphagia, or swallowing disorder, is a common symptom of different neurological diseases. The assessment traditionally focuses on describing the mechanism of alteration and the degree of severity, but rarely does it explore the impact it has on the quality of life of the person.*

Method: *Twenty-seven people with neurogenic dysphagia (60.04±14.14 years, 10 men) were assessment with the self-administered quality of life questionnaire (SWAL-QOL-Ch), which was adapted in Chile. It was compared with a control group of 113 participants (51.42±7.62 years, 46 men) and the influence of sex and etiology was determined.*

Results: *Patients with neurogenic dysphagia presented significant differences in all SWAL-QOL-Ch scales in relation to the control group. In the variable sex, difference is observed only in "duration of feeding", no differences were observed by etiology.*

Conclusions: *Patients with neurogenic dysphagia have altered their quality of life, especially in relation to the time they take to eat.*

Key words: *Deglutition Disorders, Quality of life, Nervous System Diseases*

INTRODUCTION

Dysphagia means the difficulty to ingest food from the mouth to the stomach (1). It can occur at any age, from newly-born to senior adults, and is a symptom of different conditions, such as congenital diseases, structural alterations and different neurological diseases, especially in Parkinson's Disease (PD), Multiple Sclerosis (MS), Amyotrophic Lateral Sclerosis (ALS), Alzheimer's Disease (AD), Huntington Disease (HD), and, with more prevalence, in Cerebrovascular Accidents (CVA) (1, 2).

The prevalence of dysphagia caused by CVA is close to 50%, with differences according to the method of evaluation used (3); in PD, using objective measures, it is close to 82% (4); 61% in patients with Traumatic brain injury (TBI) (5); and 100% during the evolution of patients with HD (6, 7).

Dysphagia is associated with increases in mortality, hospitalization time, dehydration, malnutrition, etc. However, it does not only affect the physical health of the person, but also her emotional levels and social participation, having an important influence on the Quality of Life (QL). Therefore,

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many people with dysphagia try not to eat in public, as they feel panic or anxiety when having to eat, and a significant part of them claim eating less than usual ⁽⁸⁾.

Evaluation of dysphagia usually includes a clinical evaluation done by a speech therapist, as well as an instrumental evaluation that includes video-fluoroscopy or videoendoscopy of the swallowing. These ways of evaluation are useful to determine the mechanisms of alteration and the degree of severity of the condition ⁽³⁾, but they cannot be used to determine the impact of the pathology in the QL of the person. The purpose of this research is to determine if the perception of the quality of life of the people with neurogenic dysphagia is altered, establishing if the sex and etiology variables have an influence on this perception.

METHOD

This research was done following the declaration of Helsinki, and it has the approval of the committee of institutional ethics. It corresponds to a quantitative, non-experimental, cross-sectional study.

Participants

27 persons with dysphagia caused by different neurological conditions participated, who were selected using a non-probabilistic for convenience methodology from different healthcare centers in the Metropolitan Region. Inclusion criteria were: having a diagnosis of neurogenic dysphagia, being Chilean and a native Spanish speaker, having sensory levels compatible with the application of the questionnaire, a score \geq to 22 points in the MiniMental Test (MMSE) ⁽⁹⁾ or 24 in the Parkinson MiniMental (MMP), and signing an in-

formed consent for their participation.

Evaluation

All participants were evaluated with the SWAL-QOL-Ch questionnaire, which was designed and validated to measure the quality of life and the consequences of dysphagia on daily life ^(11, 12).

The SWAL-QOL-Ch is a self-administered questionnaire that provides information about the functional impact of the swallowing conditions. It has 44 items that evaluate different domains affected in a person with dysphagia. Items were grouped in ten scales of lifestyle and one of symptoms. Scales correspond to: overload or general difficulty to eat, food selection, eating duration, eating desire, fear of eating, sleep, fatigue, communication, mental health and social impact.

Items are measured in relation to the frequency of appearance of the symptoms, with a score from 1 to 5, where 1 is given to the worst and 5 to the best quality of life. Then, each scale is transformed to a percentage scale from 0 to 100, where 100 corresponds to the most favorable and 0 to the least favorable ⁽¹³⁾.

Statistical analysis

For the statistical analysis, the software R was used ⁽¹⁴⁾. For the first analysis, the answers of the sample of people with dysphagia were compared to the answers of a previous study that applied the same instrument to 121 people without dysphagia⁽¹⁵⁾. For this purpose, the average obtained by each participant in all answers of the instrument was analyzed, and 8 outliers were eliminated (subjects located over or under 1,96 units of DE

from the average). The final sample for this control group was formed by 113 participants (median age 51.42, DE = 7.62, 67 women and 46 men). The dependent variable observed corresponded to the transformation of the gross total score for each scale to a percentage, in order to compare the different dimensions of the instrument with the same metrics. Due to the difference in sample size between the control group and the group of patients with dysphagia, tests of just one sample were selected for all relevant scales. Therefore, the scores of the patients with dysphagia were compared to an obtained reference value for

each relevant dimension in the control group. However, as many contrasts did not fulfill the assumptions of normality of the student t test, the non-parametric Mann-Whitney test was used. For each scale, the median of the group of patients with dysphagia was compared to the reference median observed in the control group.

RESULTS

The SWAL-QOL-Ch was answered by 27 participants. Table 1 shows the demographic characteristics of this group.

Table 1. Characteristics of the participants

| Characteristic | Women (n=17) | Men (n=10) |
|-------------------------|-------------------------|-----------------------|
| <i>Age</i> | 61.24±13.48 years | 58.00±16.45 years |
| <i>Diagnosis</i> | | |
| CVA | 8 | 8 |
| Parkinson's disease | 2 | 0 |
| Huntington's disease | 4 | 1 |
| Multiple sclerosis | 2 | 0 |
| Encephalocranial trauma | 1 | 1 |
| <i>Education</i> | 10.88±2.98 years | 12.90±3.51 years |
| <i>MMSE</i> | 27.00±1.56 | 27.00±2.12 |
| <i>MMP</i> | 24.20±0.84 | 24.00±0.00 |

For the variable of sex, no important differences by age ($t(25) = .55, p = .58$) and educational level ($t(25) = -1.59, p = .12$) were found.

In relation to the diagnoses, these were: CVA, 59,2%; Parkinson's disease, 7,4%; Huntington's disease, 18,5%; multiple sclerosis, 7,4%; and encephalocranial trauma, 7,4%.

The average scores and the median for the control group and for the group of people with dysphagia for each of the scales are presented below.

Table 2. Average scores for control group and dysphagic group in SWAL-QOL-Ch.

| Scale | Control | | Dysphagic | | Mann-Whitney p |
|---------------|---------|--------|-----------|--------|-------------------|
| | Average | Median | Average | Median | |
| Overload | 97.7 | 100 | 57.41 | 50 | <0.001 |
| Duration | 92.3 | 100 | 51.11 | 50 | <0.001 |
| Hunger | 92.68 | 100 | 60 | 53.33 | <0.001 |
| Symptoms | 94.32 | 94.29 | 65.82 | 64.29 | <0.001 |
| Selection | 94.16 | 100 | 56.3 | 60 | <0.001 |
| Communication | | | | | |
| n | 92.57 | 100 | 55.93 | 60 | <0.001 |
| Fear | 97.43 | 100 | 65.19 | 65 | <0.001 |
| Mental health | 99.61 | 100 | 62.52 | 68 | <0.001 |
| Social | 99.65 | 100 | 62.78 | 68 | <0.001 |
| Fatigue | 76.58 | 80 | 63.21 | 66.67 | 0.002 |
| Sleep | 76.46 | 80 | 60 | 60 | 0.002 |

For all scales, an important difference between the group of patients with dysphagia and the control group has been observed.

Next, the Mann-Whitney tests were taken for each scale, considering only patients with dysphagia, comparing men and women first, and then patients with dysphagia regrouped in two types of diagnosis: non-progressive (n=18, that included 16 patients with CVA and 2 TBI) and progressive (n=9, that included 2 patients with PD, 2 MS and 5 HD). The results of these tests can be seen in Tables 3 and 4.

Table 3. SWAL-QOL-Ch scores, compared by sex variable.

| Scale | Women | Men | Mann-Whitney p |
|---------------|--------------|--------------|-------------------|
| | Mean and DE | Mean and DE | |
| Overload | 54 (23.8) | 61.67 (27.9) | NS |
| Duration | 42 (25.4) | 62.5(24.9) | 0.028 |
| Hunger | 54.67 (24.1) | 66.67 (20.6) | NS |
| Symptoms | 62.29 (21.5) | 70.24 (22.3) | NS |
| Selection | 52.67 (28.4) | 60.83 (20.6) | NS |
| Communication | 48.67 (25.0) | 65 (26.4) | NS |
| Fear | 60 (24.7) | 71.67 (23.9) | NS |
| Mental Health | 54.93 (32.3) | 72 (24) | NS |
| Social | 63.2 (29.7) | 62 (20.6) | NS |
| Fatigue | 60.89 (24.8) | 66.11 (21.9) | NS |
| Sleep | 62 (29.5) | 57.5 (22.6) | NS |

In the women's group, the lowest score of quality of life was observed in the scale of "duration of eating", which corresponds to the only scale that presents important differences to the men's group. The best scores are found in "social impact" for women and "mental health" in men. No differences are found in the other scales.

Table 4. SWAL-QOL-Ch scores, compared by etiological variable.

| Scale | Non progressive | Progressive | Mann-Whitney p |
|-------------------|-----------------|--------------|-------------------|
| | Mean and DE | Mean and DE | |
| Overload | 56.11 (23.5) | 60 (30.4) | NS |
| Duration | 50.56 (24.6) | 52.22 (32.3) | NS |
| Hunger | 56.67 (23.4) | 66.67 (22.1) | NS |
| Symptoms | 65.56 (19.7) | 66.35 (26.7) | NS |
| Selection | 55.56 (20.6) | 57.78 (33.8) | NS |
| Communicatio n | 56.11 (26.6) | 55.56 (27.8) | NS |
| Fear | 65.83 (23.2) | 63.89 (28.7) | NS |
| Mental health | 57.11 (27.6) | 73.33 (32.4) | NS |
| Social | 60 (19.9) | 67.11 (35.2) | NS |
| Fatigue | 63.6 (21.6) | 62.22 (27.6) | NS |
| Sleep | 57.22 (23.9) | 65.56 (31.2) | NS |

When analyzing the sample by non-progressive and progressive etiology, no differences between groups is observed. In both, the "duration of eating" scale is their lowest score. The one with the highest score is "fear of eating" in the non-progressive group and "mental health" in the group of progressive etiologies.

DISCUSSION

Many studies have demonstrated that there is little relation between the traditional clinical evaluations of the diseases and those focused on the patient, their performance and well-being. Dysphagia is no exception, as the focus of doctors has been on the description of how physiological parameters are affected, rather than how this condition affects the psychosocial aspects of the individual.

In this context, the SWAL-QOL-Ch has a demonstrated validity, taking into account the fact that it is easy to take and to answer, it can also be self-administered or it can be administered with the help of a facilitator, if the patient has motor, cognitive and/or communicative difficulties ^(11, 12).

Its application has extended to different health conditions that have dysphagia among their main symptoms, such as: head and neck cancer ⁽¹⁶⁾, oculopharyngeal muscular dystrophy ⁽¹⁷⁾, amyotrophic lateral sclerosis ⁽¹⁸⁾ or Parkinson's disease ^(19, 20), in which it has even proved to be useful as a measure of the result of the treatment ⁽²¹⁾.

This paper shows that patients with dysphagia caused by a neurological damage see the quality of their lives altered compared to control subjects. Moreover, it also shows that the perception in relation to the quality of life does not depend on the variables of sex and etiology. However, one variable which was not considered in this study, and that has shown to have an impact in the quality of life, is the time of evolution or stage of a particular condition ⁽¹⁹⁾, a factor that has to be considered in future research.

Although the results obtained are promising when describing the percep-

tion of the quality of life of the people with dysphagia in Chile, it is important to view this data cautiously, because of the small size of the sample. New studies that include a higher number of participants and a more equal stratification by etiology must be developed.

In the present health context, taking into account an increased life expectancy and thus a higher prevalence of chronic and neurodegenerative conditions, the evaluation of quality of life and other psychosocial parameters become especially relevant in the healthcare process provided to people with dysphagia, with the objective of understanding the multidimensional nature of the disability situation of each user and therefore offer treatments that prove genuinely effective and relevant to the reality of each one of them.

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