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Caregiver Perception of Quality of Life in Neurological Patients with Dysphagia

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ABSTRACT

Background: Patients with neurological conditions often present with oropharyngeal dysphagia, which impacts their quality of life. Many of these patients require assistance from a caregiver for their complex health needs. The goal of this study was to evaluate patient-caregiver agreement in the perception of the physical, functional, and emotional burden of dysphagia in the patient.

Methods: Fifty-two adult patients with oropharyngeal dysphagia of neurological etiology and respective caregivers responded to the European Portuguese version of the Dysphagia Handicap Index (EP-DHI) questionnaire independently. Caregivers were asked to respond based on what they thought would be the answer given by the patient.

Results: The study found statistically significant differences in responses between patient and caregiver in the functional (14.7 ± 10.4 vs. 12.7 ± 9.2, $P = .03$) and emotional (12.0 ± 9.4 vs. 10.4 ± 8.9, $P = .02$) subscores of the EP-DHI. Although no statistically significant differences in total score and physical score between patient and caregiver were found, spouses as caregivers tended to undervalue the emotional subscale (9.4 ± 7.3 for patients and 7.7 ± 6.2 for caregivers, $P = .01$), and children underrated the functional subscale (16.9 ± 11.4 by patients and 13.2 ± 10.0 by caregivers, $P = .02$).

Conclusion: Caregivers are a reliable proxy in evaluating the general and physical impacts of dysphagia on quality of life in patients with neurological conditions. However, they undervalue the functional and emotional burdens.

Keywords: Caregivers, deglutition disorders, dysphagia, quality of Life

Introduction

Oropharyngeal dysphagia (OD) refers to any disturbance in the swallowing physiology of the upper digestive tract. It may include any abnormality in the formation and propulsion of the food bolus in the oral phase, as well as bolus passage, swallow response, and closure of the airway in the pharyngeal phase,[1,2] and can lead to airway invasion with penetration or aspiration.

Oropharyngeal dysphagia can result from a variety of medical conditions, including stroke, head and neck cancer, or progressive neurologic disease, and may affect multiple aspects of a person's life, including work, social life, and overall quality of life (QoL).[2] It can result in malnutrition and increased pulmonary compromise and mortality.[3-5] Due to the underlying condition, patients may become dependent on a caregiver for support and assistance with daily activities in varying degrees.[6]

The Dysphagia Handicap Index (DHI) was created by Silbergleit et al to provide a reliable and clinically relevant patient-reported outcomes tool for dysphagia. It evaluates the effects of dysphagia of any cause in 3 domains: physical, functional, and emotional.[7] The European Portuguese version of the DHI (EP-DHI) has been adapted and validated.[8]

The involvement of family members and caregivers in the treatment decisions for patients with dysphagia is crucial to obtain the best possible care. Many of these patients are dependent on a caregiver for daily living activities, as they may present with complex health needs and increasing limitations to their

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autonomy due to their base pathology.[9] In complex conditions of neurological etiology, dysphagia may not be a major priority on the list of health issues both patients and caregivers have to handle daily,[10] thus it is important to determine if this issue is being sufficiently supported.

There is some literature focusing on caregivers of patients with dysphagia, assessing the burden of dysphagia on caregivers,[9-13] exploring the caregiver experience, and their health and QoL in their role as a caregiver. Studies on reliability in caregiver response in quality of life measures in neurological conditions have had variable outcomes; some found moderate reliability while others had variations, particularly in subjective symptoms.[14-16] However, specific studies on patient-caregiver agreement regarding dysphagia impact on quality of life are scarce.

The goal of this study was to evaluate the reliability of the caregiver as a proxy for the patient's perception of the physical, functional, and emotional burden of OD, and assess factors that may impact this correlation.

Methods

Participants were recruited using a convenience sample of adult patients with OD of neurological etiology observed in the Dysphagia consultation in the Otorhinolaryngology department, along with their respective caregivers.

The inclusion criteria for the study group were (1) patient with OD of neurological etiology accompanied by the informal caregiver, (2) age above 18 years, (3) native speaker of European Portuguese, and (4) the ability to independently respond to the questionnaire questions. For the purpose of this study, a caregiver is defined as a family member: partner, parent, child, or other family member, who lives at home with the dysphagia patient and is not paid in their caregiver role.

Exclusion criteria were (1) poor auditory comprehension, (2) cognitive impairment, and (3) difficulty in reading and/or understanding Portuguese.

Clinical information, including patient gender, age, presence of dysarthria, and classification in the Functional Oral Intake Scale (FOIS)[17] was collected, as well as caregiver gender, age, and relationship with the patient. Patients and caregivers responded to the EP-DHI questionnaire independently at the same moment, blinded from each other's answers. Caregivers were asked to respond based on what they thought would be the answer given by the family member with OD.

Main Points

- Though in recent years focus has been placed on caregivers of patients with complex illnesses causing dysphagia, data on their perception of the patient's quality of life is still lacking.
- This study aims to investigate how the caregiver's perception correlates with the patient's self-reported quality of life burden caused by their dysphagia, assessed through the Dysphagia Handicap Index (DHI) questionnaire.
- This study has found excellent correlation between the patient's and respective caregiver's score on the DHI total score and physical subscore, but in the emotional and functional subscores the caregiver tends to undervalue the burden of dysphagia.
- In conclusion, caregivers are a reliable proxy in evaluating the impact of dysphagia on quality of life in patients with neurological illnesses. However, they may slightly undervalue the functional and emotional burdens.

The EP-DHI is the European Portuguese version of the DHI, an instrument composed of 25 items divided into 3 subscales: physical, functional, and emotional. The physical subscale includes 9 items related to the perception of physical discomfort caused by dysphagia, the functional subscale includes 9 questions that focus on the impact of dysphagia on daily activities, and the emotional subscale includes 7 statements evaluating the emotional toll caused by dysphagia. For each statement, responders were required to select an answer out of 3 options: never, sometimes, always, with values of 0, 2, and 4 points respectively. Thus, the total score may vary from 0 to 100 points, both the physical and functional subscales range from 0 to 36, and the emotional scale may reach a maximum of 28 points. At the end of the questionnaire, participants were asked to classify the severity of dysphagia from normal swallow (0) to severe (7) using a 7-point interval scale proposed by Silbergleit et al.[7]

Dysarthria was diagnosed using Duffy's criteria,[18] and for the purpose of this study classified as a binary (present/absent) variable. All participants, patients and respective caregivers, provided written informed consent to participate in this study. This project was approved by the Ethics Committee of Centro Hospitalar Universitário do Porto / Instituto de Ciências Biomédicas Abel Salazar (Approval no: 2019.041, Date: July 7th 2019).

Statistical analysis was performed with the SPSS software, version 26 (IBM SPSS Corp.; Armonk, NY, USA) . To compare results between patients and caregivers, the Related Samples Wilcoxon Signed Rank Test was used. All tests were applied with a degree of confidence of 95%.

Results

Sociodemographic Data

Fifty-two patients with OD of neurological etiology and respective caregivers were included in this study. Twenty-eight (53.8%) were male and 24 (46.2%) female, with a mean age of 62.5 ± 17.6 years. Average FOIS was 5.4 ± 0.9. Thirty-two patients (61.5%) presented with dysarthria, and 20 (38.5%) without dysarthria.

The underlying neurological diagnoses were varied: 16 patients with Amyotrophic Lateral Sclerosis, 10 patients post-stroke, 6 with Familial Amyloid Polyneuropathy, 6 with Parkinson's Disease, 4 with Friedreich's Ataxia, 4 with Multiple Sclerosis, 3 with Huntington's Disease, 2 with Type 2 Spinal Muscular Atrophy, and 1 with Duchenne Muscular Dystrophy, and 1 with Progressive Multifocal Leukoencephalopathy.

Of the caregivers, 43 (82.7%) were female, and 9 (17.3%) were male, with a mean age of 47.3 ± 15.3 years. Twenty-eight (53.8%) of caregivers were spouses or partners (21 wives and 7 husbands), 21 (40.4%) adult offspring of the patient (19

daughters and 2 sons), 2 (3.8%) were a parent, and 1 (1.9%) a sibling.

Overall European Portuguese version of the Dysphagia Handicap Index Scores

There were no statistically significant differences between patient and caregiver overall score (38.8 ± 24.2 vs. 36.6 ± 22.0, respectively), or physical subscale (13.2 ± 8.0 vs. 13.3 ± 7.2). However, statistically significant differences could be found in both the functional (14.7 ± 10.4 for the patient vs. 12.7 ± 9.2 for the caregiver, *P* = .03) and emotional subscales (12.0 ± 9.4 vs. 10.4 ± 8.9, *P* = .02). These results are represented in Table 1.

When comparing individual questions, only 2 questions, both from the functional subscale, had statistically significant differences:

- The item "It takes me longer to eat a meal than it used to." had a mean score of 2.4 ± 0.8 for patients and 2.1 ± 0.9 for caregivers, with a *P* value of .02.
- The item "I avoid eating because of my swallowing problem" had a mean score of 1.6 ± 0.8 for patients and 1.4 ± 0.6 for caregivers, with a *P* value of .01.

Presence of Dysarthria

When dividing the patients into those with and without speech abnormalities, statistically significant differences in the functional and emotional subscales, as well as in the total EP-DHI scores, between patients and caregivers were observed. However, such differences were not observed within the group without dysarthria (Table 2).

Caregiver Relationship and Gender

When comparing results according to the relationship between the patient and respective caregiver, statistically significant differences were found in the functional subscale results when the offspring is the caregiver (16.9 ± 11.4 vs. 13.2 ± 10.0, *P* = .02), and in the emotional scale when the spouse is the caregiver (9.4 ± 7.3 vs. 7.7 ± 6.2, *P* = .02), as reported in Table 3. Parent (n = 2) and sibling (n = 1) had too small samples for this assessment.

Discussion

The aim of this study was to assess caregiver reliability in the perception of the physical, functional, and emotional burden of OD on the patient they care for. Caregivers support family members with a range of health concerns beyond dysphagia, and dysphagia may not be a priority in complex conditions etiology.[10,19] This is seen more in patients with dysphagia of neurological etiology, while in head and neck cancer patients, dysphagia is often a major concern.[4]

Table 1. EP-DHI Total and Subscale Score Mean and Standard Deviation (SD), by Patients and Caregivers, and Statistical Difference

EP-DHI Results (mean ± SD)	Patient	Caregiver	*P*
Physical subscale	13.2 ± 8.0	13.3 ± 7.2	.87
Functional subscale	14.7 ± 10.4	12.7 ± 9.2	**.03**
Emotional subscale	12.0 ± 9.4	10.4 ± 8.9	**.02**
Total	38.8 ± 24.2	36.6 ± 22.0	.06

P < 0.05 statistically significant difference

Studies on caregivers in literature mostly focus on caregiver burden and quality of life.[9-13] Literature on caregiver perception of overall quality of life of patients has inconsistent results, with some studies reporting moderate agreement, and others showing higher embarrassment and shame by caregivers, and less reliable assessment in subjective symptoms.[14-16]

Data on patient-caregiver agreement in dysphagia is scarce, with 1 study evaluating patient-caregiver correlation in the Swallowing Quality of Life Questionnaire in Parkinson Disease and finding no statistical difference between patients and caregivers.[20]

This study revealed that caregivers generally have an accurate understanding of the physical toll of OD, but underestimate the functional and emotional impacts. In particular, caregivers undervalue the statements "It takes me longer to eat a meal than it used to," and "I avoid eating because of my swallowing problem," in the functional subscale. When dividing patients into subgroups according to the presence of dysarthria, it was found that this underestimation of the functional and emotional burdens of dysphagia was only statistically significant in this group. Even mild dysarthria can have a negative impact on leisure activities, social relationships, and employment, and neurological diseases can affect speech intelligibility, perceived speech severity, and communication participation.[21] These factors may contribute to a less accurate assessment by the caregiver of the patient's quality of life, as they may communicate less when compared to patients without

Table 2. EP-DHI Total and Subscale Score Mean nd SD, by Patients and Caregivers, and Statistical Difference, Divided in 2 Groups According to the Presence of Dysarthria

	Patient with Dysarthria			Patient Without Dysarthria		
EP-DHI Results (mean ± SD)	Patient	Caregiver	*P*	Patient	Caregiver	*P*
Physical subscale	13.4 ± 7.2	13.0 ± 6.7	.72	12.9 ± 9.3	13.8 ± 8.1	.45
Functional subscale	15.6 ± 11.0	12.9 ± 9.4	**.01**	13.3 ± 9.7	12.2 ± 9.3	.97
Emotional subscale	12.3 ± 9.1	10.6 ± 8.5	**.02**	11.6 ± 10.0	10.1 ± 9.8	.29
Total	39.5 ± 23.7	37.7 ± 20.7	**.047**	37.8 ± 25.4	34.6 ± 24.8	.55

P < 0,05 statistically significant difference

Table 3. EP-DHI Total and Subscale Score Mean and SD, by Patients and Caregivers, and Statistical Difference, Comparing Responses by Spouses and Children

EP-DHI Results (Mean ± SD)	Patient	Caregiver	*P*
Physical subscale			
Spouse (n = 28)	11.6 ± 7.7	11.8 ± 7.3	.68
Child (n = 21)	15.0 ± 7.7	14.9 ± 6.2	.70
Functional subscale			
Spouse (n = 28)	12.8 ± 9.7	12.4 ± 8.8	.55
Child (n = 21)	16.9 ± 11.4	13.2 ± 10.0	**.02**
Emotional subscale			
Spouse (n = 28)	9.4 ± 7.3	7.7 ± 6.2	**.02**
Child (n = 21)	14.7 ± 10.7	12.3 ± 9.9	.32
Total			
Spouse (n = 28)	31.7 ± 19.4	32.5 ± 18.7	.11
Child (n = 21)	45.5 ± 26.8	39.8 ± 23.7	.17

P < 0,05 statistically significant difference.

communication abnormalities. However, the limitations of this study must be taken into account to interpret these results correctly. Firstly, patients were divided as with or without dysarthria, but the degree of severity of dysarthria was not taken into account. Furthermore, when dividing patients into these 2 groups, the sample sizes became small (32 and 20 patients, respectively), which may have impacted the absence of statistically significant findings. Other limitations of this study were the very small sample sizes for parent and sibling caregivers that did not allow for subgroup analysis, and the absence of data on patient cognitive function and time spent on patient care by each caregiver, which might influence the reliability of their response.

When focusing on the familial relationship between patients and caregivers, it was found that spouses tended to undervalue the emotional subscale, and children the functional subscale. A study on caregiver burden based in Korea[12] found that when caring for patients with dementia, spouse caregivers perceived a higher overall burden, social activity restriction, health-related burden, and psychosocial burden than adult children caregivers, as well as negative changes in care recipient and caregiver relationships. However, the authors reinforce that the cultural tradition in Korea dictates that care for aging or frail parents be provided by adult children, and spouses may be less prepared for this role. Studies have found that men perceive less caregiving burden than women, and sons as caregivers report the lowest burden of care.[12,13]

More studies are necessary to replicate and better interpret these findings of differences in assessment of patients' QoL by caregivers of different familial status and gender, and whether their perception is influenced by their own burden.
Caregivers are a reliable proxy in evaluating the general and physical impacts of dysphagia on quality of life in patients with neurological conditions. However, they undervalue the functional and emotional burdens.

Data Availability Statement: The data that support the findings of this study are available on request from the corresponding author.

Ethics Committee Approval: Ethical committee approval was received from the Ethics Committee of Centro Hospitalar Universitário do Porto / Instituto de Ciências Biomédicas Abel Salazar (Approval no: 2019.041, Date: July 7th 2019).

Informed Consent: Written informed consent was obtained from the participants, patients and respective caregivers who agreed to take part in the study.

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