Observational Study

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Dysphagia and Quality of Life: A Cross-Sectional study of patient and caregiver perspectives

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Abstract

Objective. This study aimed to simultaneously explore the perception of dysphagia from both patient and caregiver perspectives, to assess its impact on quality of life and provide insights for the development of effective, individualized rehabilitation strategies.

Materials and Methods. A total of 160 participants were enrolled, including 80 patients with dysphagia of heterogeneous etiology and 80 caregivers. Patients completed the Italian Dysphagia Handicap Index (I–DHI), while caregivers filled out the Caregiver Mealtime and Dysphagia Questionnaire (CMDQ). Questionnaire data were compared with results from the Fiberoptic Endoscopic Evaluation of Swallowing (FEES), using the Penetration–Aspiration Scale (PAS).

Results. Patients showed limited knowledge of dysphagia symptomatology (58.1%), adequate coping abilities (61.5%), and preserved emotional stability (62.9%). Caregivers demonstrated a clear understanding of the problem (61.5%) and high adherence to speech therapy recommendations (74.8%). Spearman's rank correlation revealed no significant associations between I–DHI and CMDQ scores, nor between Oropharyngeal Dysphagia Severity (ODS) and PAS (rs = 0.236). Cluster analysis indicated significant effects of diagnosis ($p = 0.003$) and educational level ($p = 0.009$) among patients, and of gender, caregiving role and educational level among caregivers (all $p < 0.001$).

Conclusions. The findings underscore the importance of integrating patient and caregiver perspectives into clinical decision-making. Dysphagia significantly affects quality of life for both groups, supporting the need for multidimensional approaches combining self-report measures with clinical and instrumental assessments. ***Clin Ter 2026; 177 (3):483-489 doi: 10.7417/CT.2026.2032***

Keywords: *Dysphagia, health-related quality of life, fiberoptic endoscopic evaluation of swallowing, self-assessment, swallowing disorders*

Introduction

The evaluation of Health-Related Quality of Life (HRQoL) is a fundamental component of clinical practice, enabling a holistic, patient-centered approach and providing a means to monitor the effectiveness of interventions. HRQoL is a multidimensional, subjective, and dynamic parameter, encompassing not only the symptoms of a specific condition but also the impact of disease on physical, social, psychological, and functional domains. This perspective has shifted healthcare from a model focused solely on curing to one centered on caring.

Building upon Ferrans' HRQoL model (1), Timmerman et al. (2) highlighted the impact of dysphagia on patient well-being, considering swallowing disorders not only as symptoms associated with other conditions but also from

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functional, emotional, social, and perceptual perspectives. Depending on severity, dysphagia may trigger malnutrition, dehydration, aspiration pneumonia, and limitations in daily activities such as meal and fluid intake. These changes can reduce quality of life, increasing discomfort, stress, anxiety, depression, and social withdrawal.

Incorporating the patient's perspective during clinical (Clinical Swallow Examination, CSE) (3) and instrumental assessments provides complementary information to obtain a more comprehensive understanding of the individual's health status. HRQoL is commonly assessed through self-report questionnaires, which are quick and easy to administer. Several instruments specific to dysphagia exist (4), and careful selection is crucial to ensure conceptual relevance, validity, and applicability. Similar tools, though fewer in number, are available for caregivers, aiming to evaluate caregiving burden, emotional state, and adherence to recommendations (5–7). Rangira (8) reported that dysphagia negatively affects caregiver quality of life in 71% of cases, causing anxiety, reduced social participation, physical and mental fatigue, and even depression or burnout. Moreover, Suzuki (9) demonstrated that greater dysphagia severity correlates with higher caregiver burden, emphasizing the need to identify and support primary caregivers in clinical pathways. Despite the extensive literature, most studies examine patient and caregiver perspectives separately or using non-specific tools. Addressing this gap, the present study aimed to simultaneously investigate the impact of dysphagia on Health-Related Quality of Life in both patients and their caregivers. By capturing these dual perspectives, the study seeks to inform more effective, individualized interventions tailored to the needs of both groups.

Materials and Methods

Study Design

This cross-sectional study was conducted at the Phoniatric Outpatient Clinic of S. Giovanni di Dio Hospital, Florence, between September and December 2024. A total of 160 participants were enrolled, comprising 80 patients with dysphagia of heterogeneous etiology and their respective primary caregivers. Approximately two weeks before the scheduled phoniatric visit, a speech-language pathologist invited participants to complete the Italian Dysphagia Handicap Index (I-DHI) (10,11) for patients and the Caregiver Mealtime and Dysphagia Questionnaire (CMDQ) (12–14) for caregivers, either via email or in person if digital access was limited. Completed questionnaires were collected on the day of the visit, when instrumental assessments of swallowing were also performed using Fiberoptic Endoscopic Evaluation of Swallowing (FEES) (15) and the Penetration-Aspiration Scale (PAS) (16–19). The study adhered to STROBE guidelines (20).

Participants

The study included 80 patient-caregiver pairs. Patients (50 males, 30 females; mean age 70.43 years) predominantly presented with oropharyngeal dysphagia, while 2 cases involved esophageal dysphagia. Demographic characteristics and dysphagia etiology of patients are summarized in Table 1.

Caregivers (24 males, 56 females; mean age 63.52 years) were mainly female (70%), most often spouses (43.7%) or daughters (15%), while male caregivers represented 30%, primarily spouses (17.5%). Inclusion criteria for all participants were age ≥18 years and ability to provide informed consent. Patients were required to have a confirmed dysphagia diagnosis and absence of consciousness disorders. Exclusion criteria included severe cognitive decline, severe psychiatric or behavioral disorders, and, for caregivers, presence of a swallowing disorder.

Variables and Data Collection

Demographic data (age, sex, educational level) were collected via questionnaire fields. Patient diagnoses were extracted from electronic medical records, while caregivers reported their role relative to the patient during the visit or telephone interview. The I-DHI and CMDQ assessed patient and caregiver perceptions of dysphagia and its impact on quality of life. These data were correlated with instrumental findings from the FEES assessment performed on the day of the visit.

FEES Protocol and PAS Scoring

FEES examinations were performed using a flexible endoscope (XION EF-N, 3.4 mm × 320 mm) mounted on a KARL STORZ SL PAL camera system. Bolus consistencies were tested in order: 1) water dyed with methylene blue (IDDSI 0), 2) pureed fruit dyed with methylene blue (IDDSI 3), and 3) solid biscuit (IDDSI 7), with 2–3 trials per consistency. A teaspoon was used for more severe dysphagia or to reduce bolus volumes. Examinations were discontinued if severe impairment of oral preparatory/propulsive phases, penetration/aspiration with residue, or absence of swallow reflex occurred. FEES recordings were analyzed using the PAS (1–8 scale), with the worst bolus score used for analysis. A feedback session was provided to each patient and caregiver after assessment.

Bias

To minimize selection and information bias, all participants were approached using an identical relational and evaluative protocol, regardless of dysphagia severity or diagnosis. Homonymous patient names were verified via date of birth and clinical history.

Sample Size

Out of 196 potential participants, 3 patient-caregiver dyads declined participation, 9 dyads did not attend and 12 subjects were excluded based on predefined criteria, resulting in a final sample of 160 participants (see Flowchart, Figure 1).

Quantitative Variables and Data Management

Collected variables included:

1. Individual and total I-DHI scores per domain (Physical, Functional, Emotional);
2. Individual and total CMDQ scores per domain (Quality of Life, Disagreement with Speech Therapist, Problem Avoidance);
3. PAS scores from FEES examinations.

Table 1. Patient Characteristics and Dysphagia Etiology

Oropharyngeal Dysphagia					
Pathogenesis of dysphagia	N. Patients	Diagnosis	Age (years) Mean value	Genre N.	
				M	F
Dismotility	18	Stroke	72,22	13	5
	17	Parkinson's disease/ Parkinsonian syndrome	75,64	12	5
	3	ALS	72,33	2	1
	2	Severe acquired brain injuries	68,5	2	
	2	Mild Cognitive Impairment	79	1	1
	3	Epilepsy	59	2	1
	3	Traumatic brain injury (TBI)	74,66	3	
	2	Thromboendarterectomy	57,5	2	
	3	Thyroidectomy	67,33		3
	1	Brain tumor	79	1	
	1	Lung cancer	80	1	
	1	Respiratory failure	67		1
	1	Friedreich's ataxia	44		1
	1	Myasthenia Gravis + Parkinson's disease	68	1	
	1	Myopathy	62		1
	1	Progressive supranuclear palsy	72	1	
	1	Septic shock complicated by multiorgan failure	20		1
	1	Cardiac ischemia	85	1	
	1	Primary dilated cardiomyopathy	77	1	
	1	Thoracic aortic dissection	82	1	
	1	Cordectomy Va laser dx	68	1	
	1	Laryngopharyngeal reflux	40	1	
	6	Functional dysphagia	69,5	2	4
Mechanical obstruction	6	Head and neck tumors	69,33	1	5
Esophageal Dysphagia					
Dismotility	1	Suspected mediastinal esophageal diverticulum	72		1
Mechanical obstruction	1	Total esophagectomy	70	1	

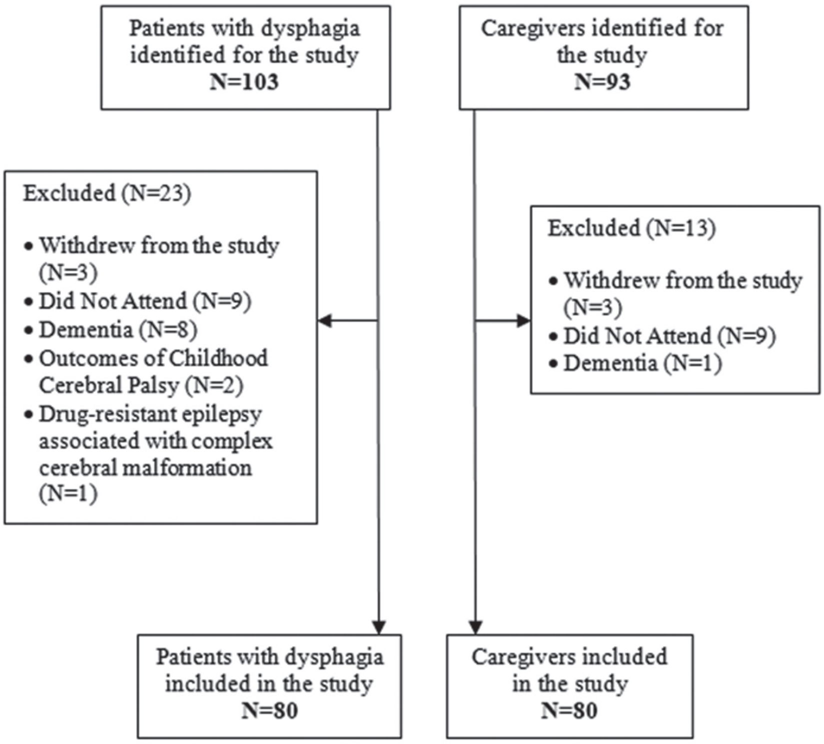

Fig. 1. Flowchart of the study sample

Data were pseudonymized, stored in password-protected cloud storage, and backed up on external devices. Each participant received a unique ID number.

Statistical Analysis

Data were reviewed by two speech-language pathologists, one clinical phoniatrician, and a statistical researcher. Statistical analyses were performed using RStudio (v4.4.2). Mean, median, and percentage distributions were computed for all questionnaire items. Higher I-DHI scores indicated poorer HRQoL and potential dysphagia, whereas higher CMDQ scores reflected a more negative caregiver perception of the disorder. Spearman's rank correlation coefficient was used to examine relationships between patient and caregiver scores and PAS findings. For both the I-DHI and CMDQ questionnaires, the interquartile range (IQR) was calculated to assess response variability. K-means cluster analysis was applied to demographic variables. Chi-square and Cramer's V tests were used to evaluate associations. Statistical significance was set at $p < 0.05$.

Results

In the I-DHI questionnaire among patients, the Physical domain responses were distributed as 58.1% "Never", 33.9% "Sometimes" and 8.1% "Always". Within the Functional domain, 61.5% responded "Never", 16.2% "Sometimes", and 22.2% "Always". For the Emotional domain, 62.9% selected "Never", 24.3% "Sometimes", and 12.9% "Always".

In the CMDQ questionnaire completed by the caregivers, a wider scoring range emerged across three domains. In the Quality of Life (Q) domain, 61.5% disagreed with the statements, 14% agreed, 9% moderately agreed, 9% fully agreed, and 6.5% were undecided. In the Disagreement with the Speech-Language Pathologist (D) domain, the distribution was 74.8% disagreement, 7.3% agreement, 7% undecided, 5.5% moderately agree and 5.3% fully agree. In the Problem Avoidance (E) domain, 86.5% disagreed, 4.2% were undecided, 3.8% agreed, 3.2% moderately agreed, and 2.3% fully agreed.

Correlations using Spearman's coefficient were conducted to compare selected items from the Emotional and Functional domains of the I-DHI with conceptually analogous items in the Quality of Life section of the CMDQ. For example, I-DHI item 1E was compared with CMDQ item 1Q; items 2E, 4E, 5E and 6E were compared with CMDQ items 2Q and 3Q; I-DHI item 3E with CMDQ 4Q; I-DHI items 6F and 7F with CMDQ items 19Q and 20Q. These comparisons yielded low correlation values, indicating an absence of meaningful association between the selected items across instruments. In contrast, intra-questionnaire comparisons within the same domain produced higher coefficients, supporting the internal consistency of each instrument. Spearman's correlation was also used to explore the relationship between the final I-DHI item, Oropharyngeal Dysphagia Severity (OD Severity) and the PAS score; here the coefficient was 0.236, again indicating lack of correlation. This latter analysis was based on 77 patients, as in three cases PAS scoring was not feasible due to severe clinical conditions at the time of the FEES examination.

Regarding variability, we calculated the interquartile range (IQR) for each domain of both questionnaires. For the I-DHI, IQR values ranged between 0 and 2: the Physical domain exhibited low variability (0.69), the Emotional domain moderate variability (1.00), and the Functional domain slightly higher variability (1.08). These findings suggest that, while patient responses regarding physical aspects of dysphagia were relatively homogeneous, responses in functional and emotional domains were more dispersed-reflecting the subjective and individual nature of these experiences. In the CMDQ, IQR values ranged between 0 and 4: the Quality of Life domain showed the greatest variability (1.650), the Problem Avoidance domain displayed no variability (most responses were "Disagreement"), and the Disagreement with the Speech-Language Pathologist domain had intermediate variability (0.875). These results indicate that caregiver perceptions of how dysphagia affects quality of life are heterogeneous and context-dependent.

For cluster analysis we converted qualitative variables into quantitative ones and applied the K-means method.

Patients

Three clusters emerged among the patients. Variables included education level (elementary = 1; middle school = 2; high school = 3; university = 4), sex (male = 1; female = 2) and type of dysphagia: obstructive mechanisms were coded as 1 for oropharyngeal and 2 for esophageal, while dysmotility-related dysphagia was coded as 3 (oropharyngeal) and 4 (esophageal).

- Cluster 1 consisted of 10 males (45.5%) and 12 females (54.5%), with mean age 71.4 years, a mean PAS of 2.82 and mean OD Severity 4.41. Oropharyngeal dysphagia due to dysmotility predominated.
- Cluster 2 included 4 males (66.7%) and 2 females (33.3%), mean age 79.5 years; mean PAS = 4.0 and mean OD Severity = 5.0; diagnoses were largely oropharyngeal dysmotility.
- Cluster 3 comprised 36 males (69.2%) and 16 females (30.8%), mean age 69 years; mean PAS = 2.58 and mean OD Severity = 2.77; primarily oropharyngeal motor dysphagia.

Figure 2 depicts the mean values by diagnosis, OD Severity and PAS for the three clusters.

From the data, Cluster 1 showed the greatest discrepancy between the objective PAS scale and the self-perceived OD Severity index. Cluster 2 included the most severe dysphagia cases, while Cluster 3 comprised the mildest forms—as confirmed by both PAS and OD Severity scores. The oldest patients were grouped in Cluster 2, the youngest in Cluster 3. The Chi-square analysis revealed no statistically significant association between sex and cluster membership ($p > 0.05$), while significant associations were found between diagnosis and cluster ($p = 0.003$), and between educational level and cluster ($p = 0.009$). These findings underscore the clinical relevance of diagnosis and schooling in determining cluster membership.

Caregivers

Among caregivers, K-means clustering identified five distinct clusters based on sex, educational level and relation-

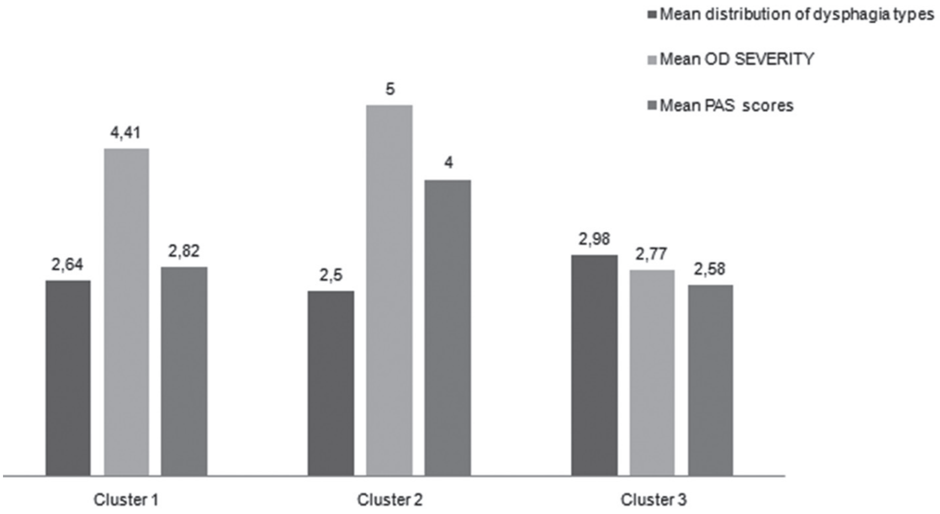

Fig 2. Cluster-specific mean values for patients.

ship to the patient (coded as: son/daughter = 1; brother/sister = 2; spouse = 3; other = 4).

- Cluster 1: predominantly female, high education, mean age 67.5 years, mostly "Other" relationship (e.g., assistant, mother-in-law, son-in-law).
- Cluster 2: younger, more male caregivers, mean age 42.3 years, medium education, mostly "sons/daughters".
- Cluster 3: mainly spouses, mean age 68.3 years, higher male proportion, moderate education.
- Cluster 4: older female caregivers (mean age 69.7 years), low education, mainly "Other".
- Cluster 5: daughters/sons (predominantly female) around mean age ~50 years, representing an intermediate group between younger and older caregivers.

Figure 3 reports mean values by relationship, education and sex for these five clusters.

Age emerged as the principal discriminant among clusters, allowing clear identification of younger, middle-aged and older caregiver groups. Although relationship type was more evenly distributed, role differences were evident—for instance, Clusters 2 and 5 both involve "sons/daughters" yet differ by age. The distribution of caregivers by age and education suggests differentiated needs and demands in dysphagia management. Chi-square tests produced highly significant results for the association of cluster with sex, educational level and caregiver–patient relationship (all $p < 0.001$). Cramer's V indicated a strong association (0.87) for cluster vs sex, and moderate-strong associations for cluster vs relationship (0.62) and vs education (0.56).

Overall, the results highlight the heterogeneity of dysphagia experiences and caregiver burden, influenced by clinical severity, demographic factors, and the dynamics of the patient–caregiver relationship.

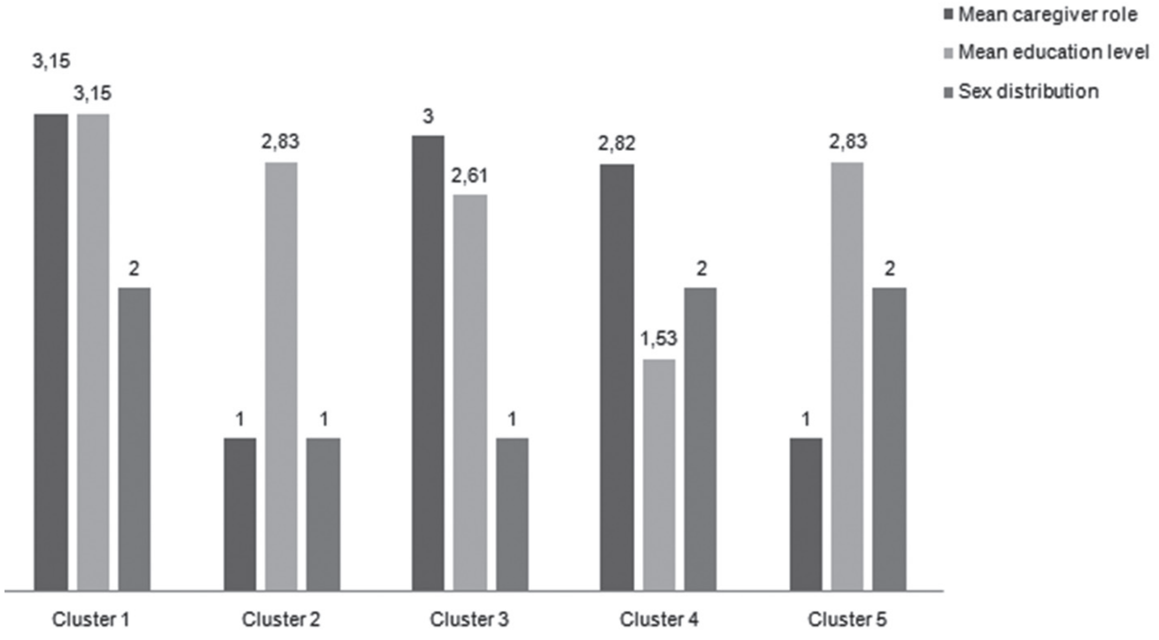

Fig. 3. Cluster-specific mean values for caregivers.

Discussion

The present study confirms that dysphagia significantly affects both patients and caregivers across physical, functional, and emotional domains. Patients generally reported low symptom awareness, likely reflecting the effectiveness of prior counseling, chronic management strategies, and adaptation to compensatory techniques. Emotional and functional experiences were more variable, suggesting that individualized assessment and tailored interventions are essential to address the unique needs of each patient. Caregivers demonstrated a high level of awareness regarding the consequences of dysphagia and implemented compensatory strategies effectively. Nevertheless, variability in caregiver responses, particularly in relation to perceived Quality of Life, underscores the importance of considering demographic characteristics, sex, educational level, and the caregiver's role in designing support strategies and clinical pathways.

The low correlation between patient and caregiver responses, as well as between subjective and instrumental measures of dysphagia, highlights the necessity of integrating multidimensional assessment tools. Reliance on either patient-reported outcomes or instrumental evaluations alone may fail to capture the full impact of swallowing disorders. Cluster analyses further demonstrated that demographic and clinical factors, including age, diagnosis, and educational background, contribute to heterogeneity in patient and caregiver experiences, reinforcing the need for personalized care approaches. Limitations of this study include its cross-sectional design, which precludes causal inferences, and the inclusion of dysphagia cases with heterogeneous etiologies, which may limit generalizability. Future research should focus on homogeneous patient populations while continuing to incorporate caregivers, given their crucial role in implementing effective interventions.

Conclusions

This study demonstrates that dysphagia exerts a multidimensional impact on both patients and caregivers. Effective clinical pathways should integrate patient- and caregiver-reported outcomes with clinical and instrumental assessments to provide a comprehensive understanding of the disorder. Interventions should be individualized, considering the patient-caregiver dyad, clinical severity, demographic factors, and educational background. A multidimensional and personalized approach is essential to optimize quality of life, enhance adherence to compensatory strategies, and support both patients and their caregivers throughout the rehabilitation process.

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Conflict of interest. The authors declare no conflict of interest.

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Ethical consideration. This study was approved by the Institutional Ethics Committee of Regione Toscana-Area Vasta Centro (ID 26922). The research was conducted ethically, with all study procedures being performed in accordance with the requirements of the World Medical Association's Declaration of Helsinki. Written informed consent was obtained from each patient and caregiver for study participation and data publication.

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