Dysphagia
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ORIGINAL ARTICLE

Cross-Cultural Adaptation and Validation of the European Portuguese Dysphagia Handicap Index

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Abstract

The Dysphagia Handicap Index (DHI) is a valid Health-related Quality of Life (HRQoL) 25-item questionnaire assessing the physical, functional, and emotional aspects of patients with oropharyngeal dysphagia (OD), of heterogeneous etiologies. The purpose of this study is to translate and validate the European Portuguese-DHI (EP-DHI). This is a prospective study that was carried out at Centro Hospitalar Universitário do Porto (CHUPorto). The generated EP-DHI was administered to 132 patients with OD and 112 healthy control subjects. 132 patients undergoing fiberoptic endoscopic examination of swallowing (FEES). 15 patients were contacted by phone, 2 or 3 weeks later after the first interview to repeat the questionnaire. The validity of concurrent criteria was evaluated by comparing the results of the EP-DHI score with the score attributed to the pathological findings found in FEES and, consequently, Functional Oral Intake Scale (FOIS). The internal consistency of EP-DHI was successful: Cronbach's alpha coefficient for total EP-DHI was 0.874. The test–retest reliability for the total and the three EP-DHI subscales obtained a Pearson's correlation coefficient ranged from 0.990 to 0.712. This study demonstrates that EP-DHI is a valid tool for self-assessment of the handicapping effect of dysphagia on physical, functional, and emotional aspects of patient's quality of life, among an European Portuguese sample.

Keywords Deglutition disorders · Dysphagia · Health-related Quality of Life · Fiberoptic Endoscopic Evaluation of Swallowing

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Introduction

Oropharyngeal dysphagia (OD) is a disturbance in the formation and movement of the food bolus from the oral cavity to the stomach, safely and effectively [1]. Swallowing difficulties are not always documented as primary medical diagnoses, but as symptoms of an underlying disease [2]. OD has a multimodal origin and its etiology may be neurological, muscular, anatomical or iatrogenic. It has a relevant prevalence in many pathologies, such as stroke, Parkinson's disease, Multiple Sclerosis, Progressive Supranuclear Palsy, Amyotrophic Lateral Sclerosis, Myotonic Dystrophy, Guillain-Barré syndrome, Myasthenia Gravis, upper esophageal sphincter dysfunction (ESS), paraneoplastic syndromes, malignant tumors, radiation treatments, post-surgical states, aging and psychogenic causes [2–8].

The actual prevalence in the adult population is often underestimated. Elderly individuals with neurological diseases, neurodegenerative diseases and head and neck cancer are considered at-risk populations. In 2012 it was estimated to affect 30–40% of the population over 65; 30 million

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European citizens over 70; 10 million individuals in Japan; 1 in 25 adults in the United States; and 1 in 9 elderly living independently in the United Kingdom. In the elderly, it is associated with a high mortality ratio [4, 9–11].

People with OD may have anterior food leak through the lips, saliva loss from the mouth, hesitation or inability to start swallowing, nasal regurgitation, food bolus trapped in the larynx/pharynx, multiple swallowing, cough, asphyxia, wet voice, weight loss, entry of food into the lungs through the trachea, increased time/duration of the meal, restrictions/exclusion of oral feeding, or need for modified dietary consistencies [2, 12]. However, the effects of OD go beyond.

Besides the physical symptoms such as swallowing disorders, the effects of OD affects numerous aspects of the individual's life, including their work, social life, and quality of life (QoL) [12–15].

In recent years, emphasis has been placed on QoL as one of the main factors to be considered in the treatment of people with dysphagia [16, 17]. Various questionnaires were conducted to assess the perception of QoL in individuals with OD. Some questionnaires are specific to the disease, such as the M.D. Anderson Dysphagia Inventory (MD-ADI) that targets patients with head and neck cancer [18] and the Dysphagia Goal Handicap (DGH) for patients with esophageal dysphagia [19]. Others are more generic, designed for dysphagia of any cause, such as the Deglutition Handicap Index [20], Swallowing QoL Questionnaire (SWAL-QoL) [21] and the Dysphagia Handicap Index (DHI) [22].

In Portugal, only the SWAL-QoL instrument has been translated and validated to assess the perception of QoL in individuals with OD due to head and neck cancer [23]. Thus, it is pertinent to perform the translation, cross-cultural adaptation and validation of a tool that can measure the disabling effects of dysphagia in different domains, whether physical, functional and/or emotional, and also assess OD of any cause.

The aim of this research is to translate, cross-cultural adapt and validate, for the European Portuguese population, a version of the Dysphagia Handicap Index (DHI).

Material and Methods

To develop the European Portuguese—Dysphagia Handicap Index (EP-DHI), the original authors of the DHI were first contacted to request their permission, via electronic correspondence. After authorization, the project was submitted to the Ethics Committee for Health of the hospital, where data were collected.

All study participants received a study information leaflet and agreed to the free and informed consent form, signing two copies: one copy for the participant and one for the researchers.

Translation Process

The translation process and development of the EP-DHI instrument comprised five procedures, based on the guidelines for translation, cultural and linguistic adaptation proposed by Beaton et al. [24].

First, the original DHI version was translated by two different translators to the Portuguese version. Second, a meeting was held with two speech therapists and one otorhinolaryngologist to analyze the translations and prepare the preliminary version of the instrument. In the third stage, the preliminary version of the questionnaire was back translated into English by two other translators, whose mother language was English. In the fourth stage, a meeting was held to prepare the Portuguese pre-final version of the DHI. In the fifth stage, the Portuguese pre-final version of the instrument was filled by 21 patients with dysphagia and, finally, after considering the opinions of the specialists and participants, the final EP-DHI was achieved.

Population

The study group involved 132 patients with OD followed at CHUPorto. The control group included a convenience sample of healthy volunteers recruited in the community where CHUPorto is located. The used non-probability sampling technique resulted on a disproportionate female/male ratio with no impact or differences on the analyzed and used results. Inclusion criteria for the study group were (i) presence of OD deriving from any etiology, (ii) age $\geq$ 18 years old and (iii) ability to independently read a written test. Inclusion criteria for the control group were (i) no history of OD, related diseases or feeding tube placement, (ii) age $\geq$ 18 years old and (iii) ability to independently read a written test.

Exclusion criteria for the clinical group were (i) poor auditory verbal comprehension; (ii) illiterate patients, those who were unable to fill out the questionnaire or were not assisted by a family member or a designed person to write the patients' answers on their behalf; (iii) presence of a cognitive impairment, mentioned in the clinical process; (iv) age < 18 years old and (v) difficulty in reading and/or understanding Portuguese. Exclusion criteria for control group were (i) history of dysphagia, head and neck malignancy/radiation therapy or surgeries; (ii) history of neurological disease and/or cerebrovascular accident; (iii) poor auditory verbal comprehension; (iv) presence of a cognitive impairment, mentioned in the clinical process; (v) age < 18 years old and (vi) difficulty in reading and/or understanding Portuguese.

Finally, to measure the test–retest reliability, the EP-DHI was filled by 15 patients twice, in a period ranging from 2 to 3 weeks. During this period, patients did not receive any medical, surgical, or behavioral intervention for swallowing disorder.

DHI Questionnaire

The DHI is an instrument composed of 25 items and three subscales: physical, functional, and emotional. The physical subscale includes 9 items that represent the perception of physical discomfort caused by dysphagia. The emotional subscale consists of 7 items that examine the emotional reactions of patients with dysphagia. Finally, the functional subscale includes 9 statements related to the impact of dysphagia in daily activities. For each item, three answers ("never, sometimes, always") are considered (with values of 0, 2, and 4 points, respectively). At the end of the questionnaire, participants are asked to classify the severity of their dysphagia using a 7-point interval scale proposed by Silbergleit et al. [22]. On this visual analogue scale, the most left answer corresponds to a "normal swallow"; from 1 to 2 is assumed as a "mild", from 3 to 5 a "moderate" and between 6 and 7 presumed as "severe" self-perceived dysphagia.

Functional Oral Intake Scale (FOIS)

The functional oral intake scale (FOIS) was developed in 2005 as a tool with very good reliability, validity, and sensitivity to objectively determine and monitor the range of oral intake of patients with neurogenic dysphagia [25]. It is an ordinal scale with seven levels (Level 1 "Nothing by mouth" in situations of severe dysphagia, to level 7 "Total oral diet with no restrictions" for healthy people) that assesses the oral intake of food and liquids. It has been the most used scale for rating the range of oral intake by patients with OD and it is used both in clinical and research settings [26, 27] as well as in various patient populations (amyotrophic lateral sclerosis, head and neck cancer, Parkinson's disease, and pediatric patients) [26, 28–30].

Validation and Statistical Analysis

Statistical analysis was performed with the Statistical Package for the Social Sciences (SPSS) software, version 26.

Instrument validity showed the differences between groups—patients with dysphagia and control group—using the Mann–Whitney test. The total score, the three subscales (physical, functional, and emotional), and the final individual auto-perception of dysphagia, were compared.

Convergent validity was assessed using Spearman's correlation, which compared the results of EP-DHI with the pathological findings found in FEES and, consequently, the FOIS.

Convergent validity was determined using Spearman's correlation, which compared the questionnaire total score with the patient's final response (self-reported dysphagia). In addition, we grouped patients according to your dysphagia severity and the results of the questionnaire were compared between groups, using the Kruskal–Wallis test.

The questionnaire reliability was tested by two methods: internal consistency and test–retest reproducibility. Internal consistency referred to the homogeneity of the questionnaire and the way the questions are related to each other. Cronbach's alpha coefficient was used to evaluate internal consistency, with an acceptable minimum value of 0.7. Test–retest reproducibility, which reflected stability over time with repeated tests, was analyzed correlating the results of the initial score and subsequent scores (after 2 to 3 weeks), using Pearson's correlation coefficient. The accepted minimum test–retest correlation coefficient was 0.7.

All tests were applied with a degree of confidence of 95%, except when otherwise indicated.

Results

Population

The study group involved 132 patients with oropharyngeal dysphagia followed at CHUPorto, 74 women (56.1%) and 58 men (43.9%) with a mean age of 60 years old. The etiology of dysphagia was heterogeneous: 73.5% had neurological origin ($n=97$), 5.3% related to and/or after head and neck surgery ($n=7$), 0.8% esophageal dysphagia ($n=1$), 11.4% gastroesophageal reflux ($n=15$) and 7.6% others/unknown. The control group included 112 healthy individuals, 89 women (76.1%) and 28 men (23.9%), with an average age of 46 years.

Reliability

The internal consistency (Cronbach's alpha) of the final version of EP-DHI for the total score was 0.949, and for each subscale: physical = 0.843, functional = 0.892, and emotional = 0.911. The correlation coefficient of the test–retest total score was 0.916: 0.886 for the physical subscale, 0.990 for the functional subscale, and 0.712 for the emotional subscale ($p<0.05$) (Table 1).

Validation

The EP-DHI total score was significantly higher for dysphagia patients compared to healthy controls (36.14 ± 20.64 for dysphagia patients and 3.17 ± 4.326 for healthy controls,

Table 1 Internal consistency and test–retest reliability of the European Portuguese – Dysphagia Handicap Index (EP-DHI)

DHI scale	EP-DHI	TEST–RETEST ($n=15$)	
	Cronbach' α ($n=132$)	Pearson correlation coefficient	Intraclass correlation coefficient (ICC)
Total	0.95	0.92	0.95
Physical	0.84	0.88	0.94
Functional	0.89	0.99	0.99
Emotional	0.91	0.71	0.83

($p<0.05$ statistical significant)

$p<0{,}001$). Moreover, when comparing the three domains' scores: physical (13.43 ± 7.31 versus 2.41 ± 2.54), functional (13.03 ± 8.99 versus 0.39 ± 1.42) and emotional (13.03 ± 8.99 versus 0.39 ± 1.42)) all three domain scores were higher in the dysphagia patients' group ($p<0.001$).

Correlation analysis of the total EP-DHI score, subscales, and final auto-perception, between dysphagia and control groups were made with the Mann–Whitney test. All values were statistically significant ($p<0.001$).

Spearman's correlation between total EP-DHI score and self-reported dysphagia had a result of 0.870.

Total and subscales scores, in severity dysphagia groups are described in Table 2.

Comparison of EP-DHI and FOIS

Spearman's correlation between total and subdomain EP-DHI scores and FOIS had the following results: total score (-0.725), physical score (-0.657), functional score (-0.793), and emotional score (-0.666). These statistically significant correlations indicate that lower levels of FOIS correspond to higher results in the EP-DHI.

Discussion

The aim of this study is to translate, culturally adapt and validate the European Portuguese version of the DHI. The obtained results show that the EP-DHI has an excellent internal consistency, and it maintained its reliability and validity. This agrees with the results of the original DHI as well as its translations into other languages [22, 24, 31–34]. The excellent correlation in the test–retest shows that the EP-DHI has high reproducibility. The internal consistency (Cronbach's alpha) for the EP-DHI total scores and physical, functional, and emotional scores was high with 0.95, 0.84, 0.89 and 0.91, respectively. Test–retest reproducibility was also high, with a Person correlation coefficient of 0.92, 0.88, 0.99 and 0.71 (Table 3).

EP-DHI showed to be a valid tool to discriminate between OD patients and healthy controls. The mean EP-DHI score for OD patients' group was 36.14 ± 20.64, approximately 32% higher than Silbergeit's mean DHI score (27.33 ± 21.18) [22] and others [32–35], but lower, approximately 40%, than the Hebrew version (38.44 ± 24.39) [31]. This difference could be explained by a higher percentage of cases with moderate to severe OD (approximately 77% of the sample) compared to the original instrument [22] (Table 4). Of the three EP-DHI domains, the physical (13.43 ± 7.31) score was higher than the functional (13.03 ± 8.99) and emotional (10.98 ± 8.40). Similar results were observed in the original and other translation studies. These findings suggest that physical aspects such as coughing, choking during meals and weight loss, have a strong impact in patient's self-perceived severity of dysphagia.

This research has some limitations such as the fact that EP-DHI was not compared to other QoL instruments. In addition, during the 2-week interval between test and retest, we could not control the natural course of the patient's disease. And finally, the number of patients per degree of severity is not homogeneous, which led to a mean EP-DHI scores substantially higher than the original instrument.

DHI has different use possibilities. We highlight its applicability as a screening tool in general population samples who are at-risk for dysphagia (i.e., geriatric, neurological and auto-immune patients) and, also, in patients undergoing treatments that have dysphagia as a comorbidity (i.e., head and neck cancer patients or other surgeries in this anatomical region). DHI can assess changes in patient's perception of pre- and post-surgical handicap associated to swallowing. Furthermore, dysphagia multimodal assessment could benefit of a caregiver-proxy questionnaire, in some cases (i.e. neurological severe patients)

Table 2 EP-DHI scores distribution according to self-reported dysphagia severity in patients with dysphagia ($n=132$)

EP-DHI	Normal swallow ($n=7$)	Mild dysphagia ($n=31$)	Moderate dysphagia ($n=77$)	Severe dysphagia ($n=17$)	p
Total	2.96 ± 3.98	22.61 ± 16.24	37.48 ± 16.91	63.14 ± 9.47	<0.001
Physical	2.21 ± 2.29	8.94 ± 5.03	14.63 ± 6.25	18.82 ± 8.52	<0.001
Functional	0.42 ± 1.51	9.12 ± 7.47	13.06 ± 8.09	23.73 ± 4.13	<0.001
Emotional	0.32 ± 1.42	5.89 ± 6.29	10.97 ± 7.15	23.07 ± 4.13	<0.001

Table 3 Comparation of the internal consistency and reproducibility between the EP-DHI and the original DHI and other languages [22, 31–35]

Domains	EP-DHI		DHI		Arabic-DHI		Persian-DHI		Italian-DHI		Hebrew – DHI	
	Internal consistence	Test–retest reproducibility	Internal consistence	Test–retest reproducibility	Internal consistence	Test–retest reproducibility	Internal consistence	Test–retest reproducibility	Internal consistence	Test–retest reproducibility	Internal consistence	Test–retest reproducibility
Total	0.95	0.92	0.94	0.83	0.95	0.88	0.73	0.95	0.90	0.99	0.96	0.82
Physical	0,84	0.88	0.78	0.77	0.88	0.88	0.83	0.97	0.76	0.96	0.88	0.84
Functional	0,89	0.99	0.91	0.86	0.89	0.89	0.71	0.96	0.82	0.98	0.91	R0.71
Emotional	0,91	0.71	0.86	0.75	0.87	0.87	0.88	0.98	0.77	0.98	0.91	0.77

Internal consistence (Cronbach's Alfa); Test–retest reproducibility (Pearson correlation coefficient)

Table 4 Comparison of dysphagia severity self-perception score with the original DHI [22]

	Normal (self-perception score 0)	Mild (self-perception score 1–2)	Moderate (self-perception score 3–5)	Severe (self-perception score 6–7)
DHI	35	65	93	20
PE-DHI	7	31	77	17

the only way of obtaining patient's perception of the impact of dysphagia in QoL. This would be a questionnaire derived from DHI, to gauge the caregiver perception of swallowing handicap, to compare and/or reinforce the patients' DHI results. Further research regarding the reliability of patient and caregiver agreement is desirable to assess and manage patients with dysphagia more effectively.

Conclusion

The results of our study indicate that EP-DHI is a valid and reliable tool among patients with oropharyngeal dysphagia and it could be used to assess the effects of dysphagia in QoL.

Appendix

Final version of the EP-DHI.

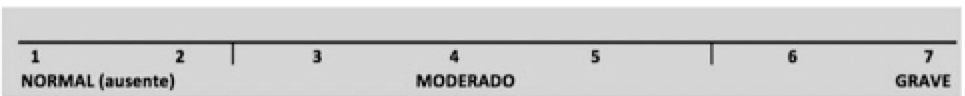
DYSPHAGIA HANDICAP INDEX – PORTUGUÊS EUROPEU

Instruções: Este questionário está dividido em **2 partes. Na primeira** parte encontra 25 frases que descrevem as características e as dificuldades sentidas quando come e bebe. Preencha com um **X,** em cada linha, de acordo com a sua experiência **no último mês. Na segunda** parte encontra uma régua com números. Assinale o número que mais se aproxima da gravidade do seu problema de deglutição.

1ª PARTE

	NUNCA (NÃO)	ÀS VEZES	SEMPRE (SIM)
1P. Tusso quando bebo líquidos.			
2P. Tusso quando como alimentos sólidos.			
3P. Tenho a boca seca.			
4P. Tenho de beber líquidos para empurrar a comida para baixo.			
5P. Perdi peso por causa do meu problema de deglutição.			
1F. Evito comer alguns alimentos por causa do meu problema de deglutição.			
2F. Alterei a forma de engolir para me facilitar a comer.			
1E. Sinto-me envergonhado/a quando como em público.			
3F. Demoro mais tempo a comer do que o habitual.			
4F. Como refeições mais pequenas devido ao meu problema de deglutição.			
6P. Tenho de engolir mais vezes antes de a comida descer completamente.			
2E. Sinto-me deprimido/a por não conseguir comer o que quero.			
3E. Não saboreio tanto a comida como antes.			
5F. Convivo menos com os outros por causa do meu problema de deglutição.			
6F. Evito comer por causa do meu problema de deglutição.			
7F. Como menos por causa do meu problema de deglutição.			
4E. Ando nervoso/a por causa do meu problema de deglutição.			
5E. Sinto-me limitado/a por causa do meu problema de deglutição.			
6E. Zango-me comigo mesmo(a) por causa do meu problema de deglutição.			
7P. Engasgo-me quando tomo medicação.			
7E. Tenho medo de me engasgar e deixar de respirar por causa do meu problema de deglutição.			
8F. Tenho de me alimentar de outra forma (p.ex. sonda) por causa do meu problema de deglutição.			
9F. Mudei a minha dieta por causa do meu problema de deglutição.			
8P. Tenho a sensação de estrangulamento quando engulo.			
9P. Tusso a comida depois de a engolir.			

2ª PARTE – GRAVIDADE DO PROBLEMA DE DEGLUTIÇÃO



Declarations

Conflict of interest The authors declare no conflict of interest in this study.

Ethical Approval All procedures performed in study were in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by ethics committee.

Informed Consent Informed Consent was obtained from all individual participants included in the study.

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