



Original article

Validation of the Deglutition Handicap Index-Informal Caregiver questionnaire

V. Malgorn^a, L. Dupont^b, M. Poncelet^c, L. Liefbrig^c, A. Lagier^{c,*}^a Université de Liège, Liège, Belgium^b Centre Hospitalier Régional de Huy, Huy, Belgium^c CHU de Liège, Liège, Belgium

ARTICLE INFO

Keywords:

Dysphagia

DHI

Hetero-assessment

Swallowing

Validation

Informal caregiver

ABSTRACT

Background: The Deglutition Handicap Index-Informal Caregiver (DHI-IC) questionnaire is a dysphagia assessment tool derived from the psychometrically validated Deglutition Handicap Index (DHI) self-reported dysphagia questionnaire in French. Like the DHI, the DHI-IC comprises 30 items, in 3 equal domains: Physical, Functional and Emotional.

Materials and methods: A prospective study included 61 patients and 61 caregivers recruited from an ENT clinic dedicated to dysphagia.

Objectives: To validate the DHI-IC as an assessment tool and to compare results with the DHI and swallowing endoscopy.

Conclusions: The DHI-IC, like the DHI, showed good internal consistency. The results indicate that it is an appropriate tool for assessing functional status, health and quality of life related to dysphagia in patients via caregiver reporting.

© 20XX

1. Introduction

Oropharyngeal dysphagia is frequent in the general population, with widely varying presentations. It may be a consequence of several pathologies, with negative impact on patients' lives, both medically and socially [1]. It can alter the preparation, propulsion and transit of the bolus in the upper aerodigestive tract and impair airway protection during swallowing [2]. For functional assessment, Patient Reported Outcome Measures (PROMs) are often the first step. The Deglutition Handicap Index (DHI) is widely used for swallowing assessment in French-speaking patients. However, the context of onset of dysphagia may raise issues of nosognosia, challenging the usefulness of this questionnaire.

The DHI was developed and validated by Woisard and Andrieux in 2006 [3], and validity was strengthened in 2022 using the COSMIN method [4].

It is a self-report questionnaire on the lines of the Voice Handicap Index [5], assessing dysphagia-related quality of life. It can be used with any kind of patient, regardless of etiology [6]. It was developed in France, in French, and there are thus no issues of translation validity or cultural differences. It is quick and easy to fill out and is widely used in clinical practice [7]. It comprises 30 items, in 3 domains (physical, functional and emotional) with 10 items each. Scores range between 0 (no handicap) and 120 (severe handicap). Each item has 5 response op-

tions, scored 0 to 4, respectively: never, almost never, sometimes, almost always, and always.

The present study aimed to validate the Deglutition Handicap Index-Informal Caregiver (DHI-IC, derived from the original DHI), which collects the opinions of caregivers regarding the manifestations of the patient's dysphagia and the impact on quality of life (Fig. 1), and is again independent of etiology. The distribution and scoring of the items are the same as in the DHI.

2. Method

This was a prospective non-interventional study, with local review board approval (n° B707201838100). Patients and caregivers were recruited during outpatient dysphagia consultations in our ENT department in 2019 and 2023. Participation was voluntary. Inclusion criteria comprised:

- presentation with swallowing disorder, confirmed on instrumental examination (swallowing endoscopy or swallowing videofluoroscopy);
- patient and caregiver sharing at least 1 meal per week;
- patient and caregiver both aged > 18 years.

* Corresponding author. Service d'ORL et Chirurgie Cervico-Faciale, CHU de Liège, avenue de l'Hôpital, 1, 4000 Liège, Belgium.

E-mail address: aude.lagier@chuliege.be (A. Lagier).

<https://doi.org/10.1016/j.janorl.2025.04.005>

1879-7296/© 20XX

What is your relationship to the patient? Spouse – child – parent – other:

Number of meals shared with the patient per week:

For each item, tick the response matching the patient's situation.

	NEVER	ALMOST NEVER	SOMETIMES	ALMOST ALWAYS	ALWAYS
Feels difficulty swallowing					
Feels food sticking or stuck in the throat					
Has difficulty swallowing liquids					
Coughs or clears the throat during or after meals					
Chokes while eating or drinking					
Has liquid or solid reflux during or after meals					
Has difficulty chewing					
Drools while eating					
Has pain in the throat when swallowing					
Food gets in the nose when drinking or eating					
Has difficulty eating certain foods					
Has to change the texture of food to be able to swallow it					
Needs longer mealtimes due to problems in swallowing					
Eats less due to problems in swallowing					
Is hungry or thirsty after a meal					
Is tired due to problems in swallowing					
Has lost weight due to problems in swallowing					
Is afraid of eating					
Has more frequent bronchitis or lung infection since the swallowing problems began					
Has more difficulty breathing since the swallowing problems began					
Avoids eating in company because of the problems of swallowing					
Is limited in personal and social life by the problems of swallowing					
Is bothered by how he/she eats at meals					
Finds eating an unpleasant time due to the problems of swallowing					
Is bothered by the problems of swallowing					
Feels other people don't understand his/her problems of swallowing					
Other people seem irritated by his/her problems of swallowing					
Is tense when eating in company, due to the problems of swallowing					
Is ashamed of the problems of swallowing					
Feels handicapped by the problems of swallowing.					

Fig. 1. Deglutition Handicap Index-Informal Caregiver questionnaire, traduction from "Déglutition Handicap Index-Accompagnant"

Patients and caregivers with moderate to severe cognitive disorder, with a Mini Mental State Examination (MMSE) score below 20/30 [8], liable not to respond reliably on the questionnaire, were excluded.

All included patients had exclusively oral feeding.

Patients underwent fiberoptic endoscopic evaluation of swallowing (FEES) [9], an instrumental procedure assessing swallowing for various consistencies according to the International Dysphagia Diet Standardisation Initiative (IDDSI) classification (<https://iddsi.org/>) [10]:

- IDDSI 4: “Usually eaten with a spoon (a fork is possible), cannot be drunk from a cup because it does not flow easily, cannot be sucked through a straw, does not require chewing, falls off spoon in a single spoonful when tilted and continues to hold shape on a plate, no lumps, not sticky, liquid must not separate from solid.”;
- IDDSI 7: “Normal, everyday foods of soft/tender textures, any method may be used to eat these foods, Sample size is not restricted at Level 7, therefore, foods may be of a range of sizes Ø Smaller or greater than 15 mm = 1.5 cm pieces (Adults), Does not include: hard, tough, chewy, fibrous, stringy, crunchy, or crumbly bits, pips, seeds, fibrous parts of fruit, husks or bones, may include ‘dual consistency’ or ‘mixed consistency’ foods and liquids if also safe for Level 0, and at clinician discretion.” (We used salted crackers or industrial sponge-cake.);
- IDDS 10: “Flows like water, fast flow, can drink through any type of teat, cup or straw as appropriate for age and skills” [10].

Five FEES scores were assessed:

- the Functional Oral Intake Scale (FOIS) [11] was designed to assess oral intake after stroke in patients with swallowing disorder, but has been extended to all types of dysphagia, regardless of etiology;
- the Dysphagia Outcome and Severity (DOSS) score [12] is a 7-point scale assessing dysphagia-related functional impairment to guide advice on feeding in terms of autonomy and type of foods;
- the Penetration-Aspiration Scale (PAS) was developed to enable reliable quantification of penetration and aspiration observed on videofluoroscopy [13], and has been successfully transposed to FEES [14];
- the Yale Pharyngeal Residue Severity Rating Scale [15] assesses pharyngeal residue after swallowing as observed on FEES, in terms of location (vallecula and pyriform sinus) and quantity (none, trace, mild, moderate, or severe);
- the Test Of Masticating and Swallowing Solids (TOMASS) [16] assesses ingestion of solids by dysphagic patients in terms of number of mouthfuls, number of mastication and swallowing cycles per mouthful, and total time; only total time was used in the present study.

After the examination, the DHI was administered to the patient and the DHI-IC to the caregiver. The caregiver was contacted again by telephone 2 weeks later for a second DHI-IC assessment. Both questionnaires were administered orally by the clinician, to ensure a constant administration modality.

The internal validity of the DHI-IC was assessed on Cronbach alpha for the 3 domains: physical, functional and emotional. Values range from 0 to 1, with > 0.71 considered acceptable. A floor effect occurs when $\geq 15\%$ of subjects have minimal scores within a sample of ≥ 50 subjects [1], and a ceiling effect when $\geq 15\%$ of subjects have maximal scores within a sample of ≥ 50 subjects [1].

Normal distribution was assessed on Shapiro–Wilk test; as most variables showed non-normal distributions, non-parametric tests were applied. Variables showed finite variance, allowing Pearson's correlation coefficient (r) to be applied, with $r = 0.3$ – 0.5 considered low, 0.5 – 0.7 moderate, and > 0.7 strong.

Mean values for normally distributed qualitative variables were compared on Student t -test, and for non-normally distributed variables on non-parametric Mann–Whitney test. The Brown–Forsythe test was used to compare variances.

Analyses used JASP software, version 0.17.2.1 (2023).

3. Results

3.1. Population

Sixty-one patients were recruited: 54.1% male, 45.9% female; mean age, 71.75 ± 11.97 years (range: 44–95 years). Table 1 shows etiologies.

3.2. Validity of the DHI-IC questionnaire

3.2.1. DHI-IC test-retest reliability

Test-retest reliability showed a strong correlation ($r = 0.942$, $P < 0.001$).

3.2.2. Internal consistency

Cronbach alpha was 0.9.

3.2.3. Floor and ceiling effects

There was a floor effect in the emotional domain, 23% of caregivers scoring 0. Overall, the DHI-IC did not show a floor effect.

There was no ceiling effect, overall or for the 3 domains.

3.3. Reliability of the DHI-IC questionnaire

3.3.1. Comparison between DHI-IC and DHI

Correlations between DHI-IC and DHI overall and per domain were highly significant (Table 2): DHI-IC domains were indeed measuring the same thing as the DHI domains.

3.3.2. Comparison between DHI-IC and the FEES gold standard

DHI and DHI-IC scores were compared to the FEES FOIS, DOSS, PAS and Yale scores on Pearson's r (Table 3). The TOMASS score was assessed only in 2023, in 28 patients; DHI and DHI-IC scores were correlated to TOMASS total time. Table 3 also shows Pearson's r for each questionnaire.

All FEES severity scores correlated more strongly with DHI-IC than with DHI, and very significantly for the FOIS and DOSS scores. TOMASS and Rosenbek's PAS scores correlated significantly with DHI-IC but not with DHI scores. The Yale scores correlated more strongly with DHI-IC than with DHI, but not significantly.

Table 1

Patient distribution according to dysphagia etiology.

Pathology	Percentage of patients
Central neurologic	18.8
Peripheral neurologic	7.2
Oncologic	17.4
Pneumologic	14.5
Presbyphagia	14.5
Other (fibromyalgia, iatrogenic, etc.)	27.5

Table 2

Pearson r correlation coefficients between DHI and DHI-IC scores, total and per domain.

Correlation DHI//DHI-IC	Pearson r
Total	0.735***
Physical domain	0.565***
Functional domain	0.635***
Emotional domain	0.756***

DHI-IC: Deglutition Handicap Index-Infomal Caregiver.

* $P < 0.05$, ** $P < 0.01$.

*** $P < 0.001$.

Table 3
Pearson *r* correlation coefficients for DHI and DHI-IC with FEES scores and TOMASS total time.

Test	Scores	FOIS	DOSS	PAS	Yale	Scores	TOMASS
DHI	N = 61 X = 29.5 σ = 21.8	−0.398***	−0.486***	0.109	0.145	N = 28 X = 23.63 σ = 16.85	0.148
DHI-IC	N = 61 X = 29.4 σ = 20.7	−0.533***	−0.594***	0.261*	0.243	N = 28 X = 24.1 σ = 17.77	0.549**

DHI-IC: Deglutition Handicap Index-Informal Caregiver; FEES: fiberoptic endoscopic evaluation of swallowing; TOMASS: Test Of Masticating and Swallowing Solids; FOIS: Functional Oral Intake Scale; DOSS: Dysphagia Outcome and Severity; PAS: Penetration-Aspiration Scale.

* *P* < 0.05.
 ** *P* < 0.01.
 *** *P* < 0.001.

3.3.3. Number of shared meals, DHI-IC and FEES severity

Caregivers were divided into 3 groups: sharing 1–5 meals per week (few), 6–20 meals (moderate), and all meals (all). On linear regression, DHI-IC responses correlated significantly with all FEES scores for caregivers sharing all meals with the patient (Table 4).

3.3.4. Laryngeal sensitivity, silent inhalation and DHI-IC

Central neurologic and oncologic etiologies incurred laryngeal sensitivity disorder, with no significant differences between DHI and DHI-IC in these cases.

A possible difference in DHI and DHI-IC scores in case of silent inhalation (i.e., Rosenbeck PAS scores of 3, 5 or 8) could not be assessed due to small sample size (*n* = 6).

4. Discussion

The present study described and assessed the psychometric properties of the DHI-IC questionnaire. In 2022, Speyer et al. reported that the psychometric properties of DHI were good [4]. DHI and DHI-IC correlated strongly, and are thus measuring the same things. Speyer et al. [4] reported good internal consistency for DHI (Cronbach α = 0.9) and possible redundancy. The internal consistency of DHI-IC was equivalent to that of the DHI questionnaire. Neither showed floor or ceiling effects; responses were also stable over time.

High DHI-IC scores correlated not only with high DHI scores, but also with most FEES severity scores. Correlations between the two questionnaires were strongest for the “global” scores, DOSS and FOIS, and weakest for the analytic dysphagia factors, penetration-inhalation and post-swallowing residue. On all scores, the DHI-IC showed better correlations with the objective FEES data than did the DHI, reaching significance for penetration-inhalation and TOMASS total time. This confirmed that the DHI-IC can assess dysphagia severity, and does so better than the DHI questionnaire, even in the present study population that

Table 4
Pearson *r* correlation coefficients between DHI-IC and FEES scores according to number of shared meals.

	FOIS	DOSS	PAS	Yale	TOMASS
Few [1–5]	−0.146	−0.181	−0.061	−0.155	0.884
Moderate [6–20]	−0.753	−0.772*	0.210	0.359	–
All [21]	−0.656***	−0.771***	0.438**	0.309*	0.496*

DHI-IC: Deglutition Handicap Index-Informal Caregiver; FEES: fiberoptic endoscopic evaluation of swallowing; TOMASS: Test Of Masticating and Swallowing Solids; FOIS: Functional Oral Intake Scale; DOSS: Dysphagia Outcome and Severity; PAS: Penetration-Aspiration Scale.

* *P* < 0.05.
 ** *P* < 0.01.
 *** *P* < 0.001.

excluded patients with moderate to severe cognitive deficits, making it less likely to be affected by central neurologic anosognosia.

On the other hand, one limitation was that the DHI-IC did not show better diagnostic performance for dysphagia with laryngeal sensitivity deficit, as in most tests of hetero-assessment of swallowing, including by health professionals, although laryngeal hypoesthesia is associated with asymptomatic laryngeal penetration and/or aspiration [17,18] and poor knowledge of the condition can lead to persistence of risky behavior.

Finally, the DHI-IC questionnaire makes it possible to take account of the views of the patient's family and other informal caregivers, who are often very actively involved. They are often present at mealtimes, and the literature testifies to the usefulness of everyday ecological mealtime observation by health professionals in many situations of cognitive deterioration [19]. A Portuguese-language dysphagia questionnaire for health professionals was recently published in Brazil [20].

The DHI-IC has the originality of targeting “informal” caregivers, who are not health professionals, as being in an expert position to assess the patient's dysphagia.

The present study showed that this expertise increased with the number of shared meals. Caregivers who know the patient well are able to detect changes in behavior and reactions during meals, which is a precious contribution in deciding whether the patient is experiencing difficulty in feeding and thus possibly in swallowing. Informal caregivers are increasingly becoming informal healthcare providers, as the health system moves toward maintaining patients at home for as long as possible, relying on the contribution of informal caregivers [21]. Mealtimes are thus shared with a family member rather than with a health professional. Moreover, the emotional domain of the DHI-IC is aimed at someone who knew the patient before the onset of the disorder and can assess the emotional impact of dysphagia. The social consequences of the patient's dysphagia directly impact such a caregiver, who is well able to answer these questions [21].

5. Conclusion

The DHI-IC is a dysphagia assessment questionnaire showing good validity and reliability, with high internal consistency. Comparison with instrumental severity assessment on FEES showed significant agreement. The DHI-IC is an effective predictor of swallowing disorder severity and also of the handicap induced by the dysphagia in daily life. It can assess everyday symptoms and impact on quality of life, even when the patient themselves cannot respond. Its contribution is undeniable in central neurologic pathology (aphasia, dementia, etc.), but the present study showed its relevance in any assessment of dysphagia, including in patients with no significant cognitive impairment. Moreover, the DHI-IC is quick and easy to administer from the clinician's point of view.

Disclosure of interest

The authors declare that they have no competing interest.

References

- [1] Timmerman A.A, Speyer R, Heijnen B.J, Klijn-Zwijnenberg I.R. Psychometric characteristics of health-related quality-of-life questionnaires in oropharyngeal dysphagia. *Dysphagia* 2014;29:183–98.
- [2] Speyer R, Cordier R, Farneti D, Nascimento W, Pilz W, Verin E, et al. White paper by the European Society for swallowing disorders: screening and non-instrumental assessment for dysphagia in adults. *Dysphagia* 2022;37:333–49.
- [3] Woisard V, Andrieux M.P, Puech M. Validation d'un questionnaire d'auto-évaluation du handicap pour les troubles de la déglutition oropharyngée (Deglutition Handicap Index). *Rev Laryngol Otol Rhinol* 2006;127:315–25.
- [4] Speyer R, Cordier R, Bouix C, Gallois Y, Woisard V. Using classical test theory to determine the psychometric properties of the deglutition handicap index. *Dysphagia* 2022;37:65–73.
- [5] Jacobson B.H, Johnson A, Grywalski C, Silbergleit A, Jacobson G, Benninger M.S, et al. The Voice Handicap Index (VHI): development and validation. *Am J Speech*

- Lang Pathol 1997;6:66–70.
- [6] Woisard V, Lepage B. The “Deglutition Handicap Index” a self-administrated dysphagia-specific quality of life questionnaire: temporal reliability. *Rev Laryngol Otol Rhinol* 2010;131:19–22.
- [7] Keage M, Delatycki M, Corben L, Vogel A. A systematic review of self-reported swallowing assessments in progressive neurological disorders. *Dysphagia* 2015;30:27–46.
- [8] Galea M, Woodward M. Mini-Mental State Examination (MMSE). *Aust J Physiother* 2005;51(3):198. [https://doi.org/10.1016/S0004-9514\(05\)70034-9](https://doi.org/10.1016/S0004-9514(05)70034-9).
- [9] Langmore S.E, Schatz K, Olson N. Endoscopic and videofluoroscopic evaluations of swallowing and aspiration. *Ann Otol Rhinol Laryngol* 1991;100:678–81.
- [10] Cichero J.A.Y, Lam P, Steele C.M, Hanson B, Chen J, Dantas R.O, et al. Development of international terminology and definitions for texture-modified foods and thickened fluids used in dysphagia management: the IDDSI Framework. *Dysphagia* 2017;32:293–314.
- [11] Crary M.A, Mann G.D.C, Groher M.E. Initial Psychometric Assessment of a Functional Oral Intake Scale for dysphagia in stroke patients. *Arch Phys Med Rehabil* 2005;86:1516–20.
- [12] O’Neil K.H, Purdy M, Falk J, Gallo L. The Dysphagia Outcome and Severity Scale. *Dysphagia* 1999;14:139–45.
- [13] Rosenbek J.C, Robbins J.A, Roecker E.B, Coyle J.L, Wood J.L. A penetration-aspiration scale. *Dysphagia* 1996;11:93–8.
- [14] Colodny N. Interjudge and intrajudge reliabilities in fiberoptic endoscopic evaluation of swallowing (FEES) using the penetration-aspiration scale: a replication study. *Dysphagia* 2002;17:308–15.
- [15] Neubauer P.D, Rademaker A.W, Leder S.B. The Yale Pharyngeal Residue Severity Rating Scale: an anatomically defined and image-based tool. *Dysphagia* 2015;30:521–8.
- [16] Huckabee M.L, McIntosh T, Fuller L, Curry M, Thomas P, Walshe M, et al. The Test of Masticating and Swallowing Solids (TOMASS): reliability, validity and international normative data. *Int J Lang Commun Disord* 2018;53:144–56.
- [17] Onofri S.M.M, Cola P.C, Berti L.C, da Silva R.G, Dantas R.O. Correlation between laryngeal sensitivity and penetration/aspiration after stroke. *Dysphagia* 2014;29:256–61.
- [18] Álvarez-Marcos C, Benito A.V, Fernández A.G, Pedregal-Mallo D, Rodríguez P.S, Rabanal L.S, et al. Asymptomatic swallowing disorders may be present in individuals with laryngeal and hypopharyngeal cancer treated with chemo-radiotherapy. *Eur Arch Otorhinolaryngol* 2022;279:995–1001.
- [19] Bäckström A, Norberg A, Norberg B. Feeding difficulties in long-stay patients at nursing homes. Caregiver turnover and caregivers’ assessments of duration and difficulty of assisted feeding and amount of food received by the patient. *Int J Nurs Stud* 1987;24:69–76.
- [20] de Oliveira G.D, Vicente L.C.C, Mourão A.M, Dos Santos S.H.G.P, de Lima Friche A.A, Bicalho M.A.C. Dysphagia screening in Brazilian older adults with dementia: content development and validation of a Questionnaire for Caregivers – RaDID-QC. *J Cross Cult Gerontol* 2024;39:457–79.
- [21] Shune S.E, Namasivayam-MacDonald A.M. Swallowing impairments increase emotional burden in spousal caregivers of older adults. *J Appl Gerontol* 2020;39:172–80.