Validation and Reliability of the French Version of the Sydney Swallow Questionnaire

Nicolas Audag, Christophe Goubau, Etienne Danse, Laure Vandervelde, Giuseppe Liistro, Michel Toussaint & Gregory Reychler

Dysphagia

Dedicated to advancing the art and science of deglutology

ISSN 0179-051X Volume 34 Number 4

Dysphagia (2019) 34:556-566 DOI 10.1007/s00455-019-09978-9





Your article is protected by copyright and all rights are held exclusively by Springer Science+Business Media, LLC, part of Springer Nature. This e-offprint is for personal use only and shall not be self-archived in electronic repositories. If you wish to selfarchive your article, please use the accepted manuscript version for posting on your own website. You may further deposit the accepted manuscript version in any repository, provided it is only made publicly available 12 months after official publication or later and provided acknowledgement is given to the original source of publication and a link is inserted to the published article on Springer's website. The link must be accompanied by the following text: "The final publication is available at link.springer.com".



ORIGINAL ARTICLE



Validation and Reliability of the French Version of the Sydney Swallow Questionnaire

Nicolas Audag^{1,2,3,4,8} · Christophe Goubau³ · Etienne Danse⁵ · Laure Vandervelde⁶ · Giuseppe Liistro⁴ · Michel Toussaint⁷ · Gregory Reychler^{1,2,4,6}

Received: 8 May 2018 / Accepted: 18 January 2019 / Published online: 1 February 2019 © Springer Science+Business Media, LLC, part of Springer Nature 2019

Abstract

Oropharyngeal dysphagia is frequently under-reported and early detection may lead to adapt strategies of rehabilitation and management decisions. The Sydney Swallow Questionnaire (SSQ), a self-reported questionnaire for the detection and quantification of oropharyngeal dysphagia, was previously adapted and validated in other languages but not in French. The purposes of this study were to develop and validate a French version of SSQ (SSQ-f) and to assess its psychometric properties. This SSQ-f, obtained by back-translation and cross-cultural adaptation, was validated in 27 patients with impaired swallowing and 27 healthy controls. After inclusion, patients filled in the SSQ-f and performed a videofluoroscopic swallow study. The penetration aspiration scale (PAS) and Dysphagia outcome and severity scale (DOSS) were assigned to assess construct validity. Sensitivity and specificity of cut-off scores for the SSQ-f were assessed by the receiver operating characteristic (ROC) curves. Moreover, the SSQ-f was repeated after 2 weeks to evaluate its test–retest reliability. The results supported that SSQ-f was considered understandable. Its total score was strongly correlated to the DOSS (r=-0.873) and to the PAS (r=0.738). It demonstrated acceptable internal consistency, with Cronbach's alpha values ranging from 0.744 to 0.956. The test–retest reliability was excellent. According to the ROC curve, cut-off scores of 118.5 or 218.5 were proposed for determining oropharyngeal dysphagia using DOSS as a reference and 755.0, using PAS as reference. No ceiling or floor effects were observed. In conclusion, the SSQ-f is a valid and reliable instrument to measure and detect oropharyngeal dysphagia in French-speaking subjects and can be used in a clinical setting.

Keywords Swallowing \cdot deglutition disorders \cdot Sydney Swallow Questionnaire \cdot Validation \cdot Assessment \cdot French translation

Nicolas Audag nicolas.audag@uclouvain.be

- ¹ Institut de Recherche Expérimentale et Clinique (IREC), Pôle de Pneumologie, ORL & Dermatologie, Université Catholique de Louvain, Brussels, Belgium
- ² Service de Médecine physique et réadaptation, Cliniques universitaires Saint-Luc, Brussels, Belgium
- ³ Unité de Pneumologie pédiatrique, Cliniques universitaires Saint-Luc, Brussels, Belgium
- ⁴ Service de Pneumologie, Cliniques universitaires Saint-Luc, Brussels, Belgium
- ⁵ Service de Radiologie, Cliniques Universitaires Saint-Luc, Brussels, Belgium
- ⁶ Haute Ecole Léonard de Vinci, PARNASSE-ISEI, Brussels, Belgium
- ⁷ Inkendaal Rehabilitation Hospital, Vlezenbeek, Belgium
- ⁸ Cliniques universitaires Saint-Luc, Avenue Hippocrate, 10, 1200 Brussels, Belgium

Introduction

Oropharyngeal dysphagia represents a frequent and severe symptom in patients [1, 2]. Its prevalence ranges from 2.4 to 80% depending on the underlying etiology, age, environment (for example, hospital, institution, or community), and way of investigation [1–11]. Because oropharyngeal dysphagia is frequently under-reported, screening and clinical assessments have an important role to determine its presence, severity, and variation [9, 12, 13]. Many assessment tools have been described in the literature [2, 13–16]. They help to adapt strategies of rehabilitation and management decisions, as well as to measure treatment efficacy for clinical purposes and research studies. Amongst them, questionnaires are increasingly used and represent ideal tools that are non-invasive and time-efficient assessments, cost-effective, easy to interpret and accurate [7, 12–14, 16]. Moreover,

questionnaires are important tools to survey attitudes, knowledge, practice, and to determine patient's preferences [17]. In 2018, International consensus on assessment of oropharyngeal dysphagia considered that self-evaluation questionnaires, initially validated in English needing to be translated and re-validated in different languages in order to be administered to an increased number of patients across the globe [18]. Several questionnaires related to oropharyngeal dysphagia have been translated and validated in other languages than their original one [19-34]. However, nowadays, only two validated forms addressing dysphagia symptoms have been translated into French, but they both specifically assess quality of life: the Swallowing Quality of Life questionnaire (SWAL-QOL) and the Deglutition Handicap Index (DHI) [6, 35]. No questionnaire currently exists to assess oropharyngeal dysphagia for French-speaking patients. After a literature review and the results of the systematic review on Psychometric Properties of Questionnaires on Functional Health Status in Oropharyngeal Dysphagia [36], we chose to validate the French version of the Sydney Swallow Questionnaire (SSQ), a patient self-reported questionnaire specifically designed to measure symptomatic severity of oropharyngeal dysphagia, to be able to widely use in clinical practice and for study application. For its original version (English), several studies have demonstrated its strong content, construct, discriminant and predictive validity and test-retest reliability in a range of different populations, for example, in head and neck cancer (HNC) patients [12, 37, 38], in elderly populations [39, 40] and in patients with Duchenne muscular dystrophy [41]. Szczesniak et al. determined a cut-off score for normality [42] and it was recently used to quantify evaluation of HNC treatment-related dysphagia [43]. Nowadays, only a Swedish translation has so far been validated in patients with oropharyngeal dysphagia, but no other translation exists [44]. For these reasons, the first aim of this study was to translate the original SSQ into French and cross-culturally adapt it for French-speaking patients. Secondly, we evaluated the validity and test-retest reliability of this French version of the SSQ (SSQ-f) in patients with impaired swallowing and in healthy controls. Finally, we determined cut-off values of dysphagia for the SSQ-f.

Method

This validation study was carried out in two parts: (1) French translation and cross-cultural adaptation of the SSQ; (2) Evaluation of the validity and the test–retest reliability of the SSQ-f in patients with impaired swallowing and healthy controls, and determination of cut-off scores.

The SSQ is made of 17 questions and has a maximum total score of 1700. For each question (except question 12),

a visual analog scale (VAS) is represented by a horizontal 100 mm line anchored at each end by extreme statements representing normal function to the left and extreme dysfunction to the right. The questionnaire included instructions asking participants to place an "X" across the scale to indicate the degree of difficulty they were experiencing related to each item [40]. The distance in millimeters from the origin of the VAS corresponded to a score from 0 to 100 for each question. Question 12 was scored between 0 and 5 based on duration of an average meal. This score was multiplied by 20 to achieve a score between 0 and 100 [12]. The total score of the questionnaire was calculated by summing up each individual score. The higher the score, the more severe the swallowing impairment. Average completion time is approximately 5 min [12, 38]. If a patient did not complete at least 15 out of the 17 questions, the questionnaire was excluded from further analysis. If a patient omitted 1 or 2 questions, an estimated score for each omitted question was calculated, based on the total score divided by the total possible score for the questions answered.

Part 1: Translation and Cross-Cultural Adaptation

The formal approval from the lead author of the SSQ was requested and obtained [12]. The SSQ-f was back-translated and cross-cultural adapted based on Beaton's guidelines [45]. In stage 1, the original version of the SSQ was translated from English to French independently by two native French bilingual translators (Translation). One of them had a medical background; the second was a professional translator who did not know the medical domain. In stage 2, the two versions were compared after consensus on the divergences in translations (Synthesis). In stage 3, the SSQ was translated back to English by an independent native English speaker, who did not participate in the first or second stage (Back-translation). This back-translation was compared to the original version (Expert committee). Finally, a pre-final version was tested for conceptual, experiential, and semantic equivalences in a representative pilot group of 50 Frenchspeaking people (Pretesting).

Part 2: Evaluation of Psychometric Properties of the SSQ-f

Participants

Study was approved by the Institutional Medical Ethics Committee (B403201628760) and registered in Clinical Trials (NCT02845362). Participants were recruited on a voluntary basis and without financial compensation. They signed a written informed consent form in accordance with the Declaration of Helsinki and the current guidelines for Clinical Good Practice. Two groups were recruited consecutively between 15th July 2016 and 15th July 2017: patients with impaired swallowing and healthy subjects.

Patients with Impaired Swallowing Patients referred for a videofluoroscopic swallow study (VFSS) in the Voice and Swallowing Clinic of the University Hospital Saint-Luc (Brussels), were prospectively recruited. Inclusion criteria were: to speak, read, and write in French, and to be older than 18 years, indicative symptoms or suspicion of swallowing difficulties. Exclusion criteria were: mental, degenerative or progressive disorders, current or former laryngectomy/tracheostomy, recent history of surgery (1 month), and be older than 80 years. The study coordinator (N.A.) had to be present during the outpatient visit for inclusion.

Healthy Subjects Healthy volunteers were recruited in nonmedical staff, university students and multi-residence housing facilities. Inclusion criteria were: to speak, read, and write in French, and to be older than 18 years. Exclusion criteria included a history of neurological or neuromuscular disease, any documented swallowing difficulties and dysphagia-related, unstable or quickly progressive disease.

Protocol

Subjects self-completed the SSQ-f (SSQ-f1) before the VFSS. The researcher (N.A.) gave oral explanation and remained physically present or available by phone to answer any remaining questions. After completing the question-naire, each patient received a package including a second SSQ-f (SSQ-f2) with a prepaid envelope. They were asked to fill in this questionnaire 15 days later at home to evaluate the test–retest reliability.

After inclusion, two videofluoroscopic series were acquired, the first with a lateral view and the second with an anteroposterior view including four images/seconds. VFFS followed recommendations from Logemann's procedures [46]. During videofluoroscopy, patients were given subsequently a liquid bolus and a more thickened bolus of 50 to 100 mL. The bolus consisted of a barium sulfate suspension (1 g/mL, Micropaque, Guerbet[®], France). When feasible and if necessary, a piece of marshmallow coated with the contrast agent was administered as well. VFSS sequences of all patients were reviewed in real time and slow motion, frame by frame and documented by an experienced radiologist. Based on this examination, the incidence of penetration and aspiration was evaluated systematically with the penetration aspiration scale (PAS) [47, 48] and the most severe score of the various trials was listed. Also, a Dysphagia Outcome and Severity Scale (DOSS) score was assessed for each patient [49].

Statistical/Data Analysis

Statistical tests were performed using the SPSS 25.0 for Windows (IBM). A descriptive analysis was performed for demographic parameters. Normality of the distribution was verified by the Kolmogorov–Smirnov test. Depending on the normality of the distribution, data were expressed as mean \pm standard deviation or median and interquartile range. Parametric or non-parametric tests were used for the comparisons.

Validity and reliability were evaluated in patients group. The construct validity was assessed using correlation, calculated by Kendall's rank correlation coefficient (Tau), between the SSQ-f1 total score and the DOSS or the PAS. Internal consistency was assessed using Cronbach's alpha coefficient with a level of ≥ 0.70 being considered as significant. Test-retest reliability measured the ability of the SSQ-f to yield consistent scores over time (15 days), given that the clinical status of the patient remained stable [50]. It was measured using an intra-class correlation coefficient (ICC). We used a two-way mixed effect, absolute agreement, single rater/measurement ICC, and values were reported according to Koo and Li [51]: values between 0.50 and 0.75 indicate moderate reliability, between 0.75 and 0.90 indicate good reliability, and greater than 0.90 indicate excellent reliability [52]. All ICC were expressed by absolute value and 95% confidence interval. Bias in the SSQ-f scores and limits of agreement were estimated using the Bland and Altman method [53].

Sensitivity and specificity for each cut-off score were assessed by the receiver operating characteristic (ROC) curves in the patients group [54]. The area under the curve (AUC) must be at least 0.70 to be adequate [50]. Ceiling and floor effects were also assessed. Both effects occur when 15% or more of the subjects respond with a highest or lowest score on the observed variable, respectively [55]. For all statistical tests, a p value lower than 0.05 was considered significant. Patients and healthy subjects were matched according to age and gender.

Results

Part 1

After completion of the back-translation and cross-cultural adaptation, the SSQ-f was considered understandable and acceptable by the expert committee. During the process, formulations and examples related to food consistencies in the French questionnaire were adapted according to the comments of the pilot group. The words "custard" in Q3 and "mornays" in Q4 were specifically adapted according to cultural eating habits, no other adaptations were necessary.

Completion rates were excellent, no omitted question were noted. The time required to fill out the questionnaire never exceeded 5 min and rating did not last more than 3 min. All patients and control subjects included in the study managed to complete the SSQ-f without assistance. The SSQ-f is available in Supplement 1.

Part 2

Twenty-seven patients were included in the final analyses (13 males, 14 females, mean age = 55.8 ± 16.6 year). Assessed (n=73), excluded (n=46), and analyzed patients (n=27) are illustrated in the flow chart (Fig. 1). All suitable participants who were approached completed the first questionnaire (SSQ-f1). Median total SSQ-f1 score for patients was 158.0 (415.0). Only two patients did not return the second form (SSQ-f2). Results and calculated measurements of SSQ-f1 and SSQ-f2 of included patients are presented in Table 1. Healthy subjects were 13 males and 14 females (mean age = 55.5 ± 16.1 year). Median total SSQ-f score for healthy subjects was 42.0 (56.2). During Part 2, we considered that the SSO-f was understood and well-accepted as reflected by the lack of no omitted question and no need for assistance to complete it. Understanding was also orally assessed after completion.

Construct Validity

SSQ-f total score was strongly correlated to DOSS (r = -0.873; p < 0.001) and PAS (r = 0.738; p < 0.001)(Fig. 2). Correlation between PAS and DOSS was significant but weaker (r = -0.514; p = 0.006).

Internal Consistency

SSO-f demonstrated acceptable internal consistency for the different questions (Cronbach's α higher than 0.70), with Cronbach's alpha values ranging from 0.744 (Q6) to 0.956 (Total score) (Table 2).

Test–Retest Reliability

The ICC for the SSQ-f total scores filled in with an interval of 15 days was 0.970 (95% CI 0.934–0.987; p < 0.001) (Table 2). Only three questions had an ICC < 0.700, namely Q3: 0.632; Q7: 0.548; and Q8: 0.669 (Table 2). The Bland-Altman plot (Fig. 3) showed that the bias between both applications of the SSO-f was 15.84. The Bland-Altman method revealed the limits of agreement for the difference between SSQ-f1 and SSQ-f2 from - 124 to 156. Except one (subject 8), all differences were between those limits.



Fig. 1 Flow chart of the study design. yr years, D/E degenerative or evolutive disorders, Postop recent history of surgery (1 month), NMD neuromuscular disorders, LT current or former laryngectomy/tracheostomy, SSQ-f French version of the

Table 1Results and calculatedmeasurements of SSQ-f1 andSSQ-f2 in patients

ID patients	Sex	Age (yr.)	PAS	DOSS	Total SSQ-f1	Total SSQ-f2	
1	M	67.4	1	5	490	395	
2	F	21.5	1	4	548	500	
3	F	33.3	1	4	703	638	
4	Μ	70.2	1	7	69	66	
5	Μ	77.2	1	6	125	132	
6	F	62.0	1	7	37	115	
7	F	56.3	1	5	454	548	
8	F	61.3	1	6	246	66	
9	М	57.6	1	7	158	57	
10	F	71.1	1	7	5	3	
11	Μ	56.2	1	7	115	186	
12	F	74.8	1	5	261	340	
13	М	46.8	1	6	122	51	
14	F	68.0	1	5	465	416	
15	М	28.8	1	7	81	92	
16	F	51.9	1	7	97	96	
17	F	55.9	1	6	151	115	
18	F	57.4	5	4	1233	1120	
19	F	75.8	1	6	420	394	
20	Μ	78.3	5	5	807	889	
21	Μ	34.4	1	7	191	259	
22	F	44.3	1	6	532	428	
23	F	22.5	1	7	12	5	
24	Μ	42.8	2	7	65	75	
25	Μ	70.3	2	7	75	80	
26	Μ	66.7	5	3	1286	ND	
27	М	55.0	2	6	31	ND	
Summary ^a	M/F: 13/14	31.6	1.5	5.9	325	283	
Ranges		21.5-78.3	1–5	3–7	5-1286	3-1120	

yr years, *F* female, *M* male, *PAS* penetration aspiration scale, *DOSS* Dysphagia outcome and severity scale, *SSQ-f* French version of the Sydney swallow questionnaire, *ND* no data

^aDepending on the normality of the distribution, data were expressed as mean or median

Ceiling and Floor Effect

No ceiling or floor effects were seen for the patients.

ROC Curve

AUC was 0.91 and 0.57 for DOSS and PAS (Fig. 4). Based on the ROC curve, a cut-off score of 118.5 (7% of total score) gave a sensitivity of 93% and a specificity of 82% and a cut-off score of 218.5 (13% of total score) gave a sensitivity of 75% and a specificity of 100%, for determining dysphagia using DOSS as a reference. In reference with the PAS, a cut-off score of 755.0 (44% of total score) gave a sensitivity of 50% and a specificity of 100% for determining dysphagia.

Discussion

Based on the results of this study, the translation and the cultural adaptation of the SSQ for French-speaking patients was considered understandable by all the people involved (expert committee, pilot group, healthy subjects as well as patients). In patients, the validity and test–retest reliability of this SSQ-f were verified. The total SSQ-f score was strongly correlated to the DOSS and to the PAS, confirming the construct validity. In the same patients, all items of the SSQ-f demonstrated acceptable internal consistency and excellent test–retest reliability. Based on the ROC curve, we obtained a sensitivity of 93% and a specificity of 82% with a cut-off score of 118.5 or a sensitivity of 75% and a specificity of 100% with a cut-off score of

Author's personal copy

N. Audag et al.: Validation and Reliability of the French Version of the Sydney Swallow Questionnaire

Fig. 2 Construct validity of the SSO-f. a Correlation between SSQ-f total score and score PAS in patients. b Correlation between SSO-f total score and score DOSS in patients. SSO-f French version of the Sydney Swallow Questionnaire, R^2 Coefficient of determination, PAS penetration aspiration scale, DOSS Dysphagia outcome and severity scale



Score Dysphagia Outcome and Severity Scale

218.5, with reference to DOSS. In reference with the PAS, a cut-off score of 755.0 gave lower results, with a sensitivity and a specificity of 50% and 100%, respectively, for determining dysphagia. Finally, neither ceiling nor floor effects were observed for the SSQ-f in patients.

The SSQ was originally developed by Wallace et al. and is already used as a specific tool for the evaluation of swallowing difficulties and oropharyngeal dysphagia in several populations of adult patients [12, 37, 39, 41]. In a systematic review on the psychometric properties of questionnaires in adults with oropharyngeal dysphagia, Speyer et al. concluded that data on the psychometric properties of the SSQ were limited in the previous studies and had to be complete [36]. Indeed, in the original paper, Wallace et al. used a moderate sample size and they only described test-retest reliability, face, content, and construct validity [12]. In oropharyngeal cancer patients, Dwivedi et al. did not evaluate any psychometric properties and no information on floor and ceiling effects were presented [37]. In other former studies about SSQ, content validity received a fair rating and no information was provided on the description of the construct or measurement properties of the comparator instruments [39, 41]. The Swedish validation evaluated, in 20 patients with swallowing problems, the construct, discriminant and predictive validity, internal consistency, and test-retest reliability [44]. Manjaly et al. considered responsiveness but they also used a small sample size (n=9) [56]. This study measured construct validity, internal consistency, test-retest reliability, ceiling and floor effect, and determined cut-off scores of the SSQ-f based on the ROC curve method.

Questions SSQ-f	Median	IQR	ICC	Cronbach's a
1	6	34	0.959	0.753
2	2	8	0.734	0.761
3	2	15	0.632	0.758
4	2	21	0.787	0.753
5	6	43	0.970	0.747
6	5	57	0.839	0.744
7	3	16	0.548	0.766
8	5	16	0.669	0.755
9	29	46	0.901	0.759
10	26	69	0.899	0.747
11	4	42	0.811	0.755
12	20	20	0.734	0.759
13	0	5	0.771	0.762
14	5	49	0.959	0.747
15	2	31	0.942	0.752
16	12	19	0.966	0.750
17	8	44	0.906	0.748
Total	158	415	0.970	0.956
Ranges	0–158	5-415	0.548-0.970	0.744-0.956

Table 2 Properties of SSQ-f1 in patients

SSQ-f French version of the Sydney swallow questionnaire, *IQR* interquartile range, *ICC* intraclass correlation

Confirming the construct validity, an inverse correlation to the DOSS and correlation with PAS were significantly observed. Former studies found similar relationship for the original SSQ with the DOSS (r=-0.70) or with a global assessment score (r=0.69) [12, 44]. Mossey-Gaston et al. reported also negative and positive correlations for the DOSS and the PAS, respectively, in a pilot study evaluating the relationship between patient perception and swallow function in patients [57]. The creators of the DOSS stated that the process of using a tool such as this may improve clinical attention to subtleties of interpreting VFSS [49].

The higher correlation between SSQ and DOSS compared to that of PAS can be explained by the functional aim of both. Moreover, it seems important to notice that the wide range possible with the SSQ (0–1700) presumably allows better discrimination in assessing dysphagia in comparison with the scores of the PAS (1–8) and the DOSS (1–7). For example, for a PAS score of 1 the range of SSQ score can be from 5 to 703, in this study, which suggests higher possible discriminative power.

N. Audag et al.: Validation and Reliability of the French Version of the Sydney Swallow Questionnaire

In previous studies on SSO, the different cut-off scores for defining dysphagia ranged from 111.0 to 234.0 (Table 3) [12, 39-42, 44]. On the one hand, our threshold values (118.5 or 218.5) obtained with the DOSS are obviously in this range. On the other hand, the values obtained with PAS (755.0) are completely out of this range. It can be explained by the different aims of PAS and SSQ (diagnostic and detection, respectively). Indeed, SSQ was demonstrated to be highly sensitive to change in response to therapy and for the detection of oropharyngeal dysphagia [12]. Contrary wise, the PAS usually aimed to confirm the presence of dysphagia because it was highly specific and poorly sensitive in patients [47, 48]. In this study, the choice of the cut-off score could represent a dilemma between, two values, 118.5 or 218.5. It makes sense that a detection test should be highly sensitive, whereas a follow-up confirmatory test should be highly specific [58]. However, it might also be relevant to take the specificity and false negative fractions into account. Indeed, it is important to understand the performance characteristics of any assessment depend on the implications of an error and the consequence of not detecting oropharyngeal dysphagia.

SSQ-f demonstrated an acceptable internal consistency for all the questions with Cronbach's alpha values higher than 0.70 [50]. In the Swedish translation of the SSQ, Arenaz Bua et al. made a factor analysis matrix, and showed that all questions except Q12 (related to how long time does it take to eat) contributed significantly to dysphagia detection [44]. We did not observe such contribution even if we

Fig. 3 Bland-Altman plot of the SSQ-f1 and the SSQ-f2. *SSQ-f* French version of the Sydney Swallow Questionnaire. Legend: Bland and Altman plot with the representation of the limits of agreement (doted line), from -1.96 to +1.96 s





Fig. 4 Area under the curve with ROC Curve. a ROC curve SSQ-f1 & DOSS. b ROC curve SSQ-f1 & PAS. *ROC* receiver operating characteristic, *PAS* penetration aspiration scale, *DOSS* Dysphagia outcome and severity scale

Studies	Populations		vr.)		Mean/median scores ^a	Cut-off scores
		Mean	Min.	Max.		
Nimmons et al. [40]	550 community-dwelling individuals	81	50.0	ND	40.0	180.0
Szczesniak et al. [42]	73 healthy subjects	58.6	22.0	82.0	59.0	234.0
Arenaz Bua and Bulow [44]	20 patients with swallowing problems; 20 healthy subjects	72.0	50.0	ND	HS:51.0 P:638.0	111.0
Archer et al. [41]	35 DMD patients; 12 healthy subjects	24.8	16.0	ND	HS:17.0 P:535.5	224.5
Holland et al. [39]	634 community-dwelling individuals	81.0	69.0	82.0	86.0	200.0
Wallace et al. [12]	45 dysphagic patients	62.0	31.0	94.0	67.0	193.0
Audag et al. [16]	27 patients with impaired swallowing; 27 healthy subjects	55.8	21.8	78.3	HS:42.0 P:158.0	118.5/218.5

DMD Duchene muscular dystrophy, yr years old, Min minimum, Max maximum, ND no data, HS healthy subjects, P patient

^aDepending on the normality of the distribution, data were expressed as mean or median

can observe that the Q12 is rarely rated as zero. Indeed, in healthy subjects, we observed only 30% that scored zero for the Q12 (vs. 26% in patients). We hypothesized that it could be explained by a cultural difference in the meal time, not be taken in account in our cultural adaptation. In a recent federal Belgian report, the mean meal time observed were 14, 21 and 26 min for the breakfast, the lunch and the dinner, respectively [59]. But, after contacting the creators of the SSQ, other authors and after analyzing results of previous studies, the results for Q12 seems comparable between different countries (Australia, Sweden and Belgium) and we commonly see mealtime of 15 to 30 min in healthy controls [42, 44]. However, in the study of Archer et al., all healthy subjects scored zero for this question, but subjects were

limited to 12 [41]. This question may need further studies with a larger sample size.

The ICC for agreement was used to verify the test-retest reliability of the SSQ-f in patients [50, 51]. Our results were very close to the Swedish translation [44]. These authors described an ICC of 0.98 for SSQ-f total scores within 2 weeks compared to 0.97 in our study. Lower ICC for Q3 (difficulty to swallow thick liquids), and Q8 (difficulty to initiate the swallowing) were similarly described. Wallace et al. also showed comparable good test-retest reliability, with total score demonstrating a mean variation of only 2% over time in a stable population with neurogenic dysphagia [12]. They described a 95% confidence interval from -11 to 7% mean change in the total score [12]. Their results can

be compared with the total score results obtained with the Bland–Altman method, showing a difference in agreement ranging from -7.3 to 9.2% in this study. The Bland–Altman method is an adequate way to observe absolute measurement errors between two repetitive tests [50]. Only one subject was outside the limits of agreement. Ceiling and floor effects occur when 15% or more of the patients respond with a highest or lowest score, respectively [55]. Similar to the Swedish version, ceiling or floor effects were not found for any question in our patients [44].

A potential limitation of this study is the lack of a validated gold standard which was already highlighted in other validation studies [12]. This poses a major problem in validating such a questionnaire. Wallace et al. used a non-validated global assessment score, combining all the clinical and radiological information to validate the SSQ [12]. Another limitation of this study is the absence of factor analysis. Also, the responsiveness (one of the three measurement properties) was not assessed and then this study did not follow COSMIN criteria.

In conclusion, the French version of SSQ is a valid and reliable instrument to measure and detect dysphagia in French-speaking patients and could be used in a clinical setting. Further studies are needed to assess its use in the evaluation and management of specific dysphagia population, and how it should help in the rehabilitation of those patients.

Funding NA received a Grant from Fund Eliane Lagast and Association Belge contre les Maladies neuro-Musculaires for his PhD Scholarship. CG is supported by the Fondation Saint-Luc. GR received a Grant from Institut de Recherche Expérimentale et Clinique, Université Catholique de Louvain.

Compliance with Ethical Standards

Conflict of interest The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical Approval All procedures performed in studies involving human participants were approved by the Institutional Medical Ethics Committee (B403201628760) and registered in Clinical Trials (NCT02845362). Participants were recruited on a voluntary basis and without financial compensation. They signed a written informed consent form in accordance with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.and the current guidelines for Clinical Good Practice.

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

References

1. Ekberg O. Dysphagia diagnosis and treatment. Medical radiology. Berlin: Springer; 2012.

- Rommel N, Hamdy S. Oropharyngeal dysphagia: manifestations and diagnosis. Nat Rev Gastroenterol Hepatol. 2016;13(1):49– 59. https://doi.org/10.1038/nrgastro.2015.199.
- Turley R, Cohen S. Impact of voice and swallowing problems in the elderly. Otolaryngol Head Neck Surg. 2009;140(1):33–6. https://doi.org/10.1016/j.otohns.2008.10.010.
- Cabre M, Serra-Prat M, Palomera E, Almirall J, Pallares R, Clave P. Prevalence and prognostic implications of dysphagia in elderly patients with pneumonia. Age Ageing. 2010;39(1):39– 45. https://doi.org/10.1093/ageing/afp100.
- Logemann JA, Rademaker AW, Pauloski BR, Ohmae Y, Kahrilas PJ. Normal swallowing physiology as viewed by videofluoroscopy and videoendoscopy. Folia Phoniatr Logop. 1998;50(6):311–9.
- Khaldoun E, Woisard V, Verin E. Validation in French of the SWAL-QOL scale in patients with oropharyngeal dysphagia. Gastroenterol Clin Biol. 2009;33(3):167–71. https://doi.org/10.1016/j. gcb.2008.12.012.
- Logemann JA, Veis S, Colangelo L. A screening procedure for oropharyngeal dysphagia. Dysphagia. 1999;14(1):44–51. https:// doi.org/10.1007/p100009583.
- 8. Lindgren S, Janzon L. Prevalence of swallowing complaints and clinical findings among 50-79-year-old men and women in an urban population. Dysphagia. 1991;6(4):187–92.
- Willig TN, Paulus J, Lacau Saint Guily J, Beon C, Navarro J. Swallowing problems in neuromuscular disorders. Arch Phys Med Rehabil. 1994;75(11):1175–81.
- Toussaint M, Davidson Z, Bouvoie V, Evenepoel N, Haan J, Soudon P. Dysphagia in Duchenne muscular dystrophy: practical recommendations to guide management. Disabil Rehabil. 2016;5:1–11. https://doi.org/10.3109/09638288.2015.1111434.
- Hill M, Hughes T, Milford C. Treatment for swallowing difficulties (dysphagia) in chronic muscle disease. Cochrane Database Syst Rev. 2004;2:CD004303. https://doi.org/10.1002/14651858. cd004303.pub2.
- Wallace KL, Middleton S, Cook IJ. Development and validation of a self-report symptom inventory to assess the severity of oralpharyngeal dysphagia. Gastroenterology. 2000;118(4):678–87.
- Etges CL, Scheeren B, Gomes E, Barbosa Lde R. Screening tools for dysphagia: a systematic review. Codas. 2014;26(5):343–9.
- Speyer R. Oropharyngeal dysphagia: screening and assessment. Otolaryngol Clin North Am. 2013;46(6):989–1008. https://doi. org/10.1016/j.otc.2013.08.004.
- Kertscher B, Speyer R, Palmieri M, Plant C. Bedside screening to detect oropharyngeal dysphagia in patients with neurological disorders: an updated systematic review. Dysphagia. 2014;29(2):204–12. https://doi.org/10.1007/s00455-013-9490-9.
- Audag N, Goubau C, Toussaint M, Reychler G. Screening and evaluation tools of dysphagia in children with neuromuscular diseases: a systematic review. Dev Med Child Neurol. 2017;59(6):591–6. https://doi.org/10.1111/dmcn.13354.
- Bai F, Ling J, Esoimeme G, Yao L, Wang M, Huang J, Shi A, Cao Z, Chen Y, Tian J, Wang X, Yang K. A systematic review of questionnaires about patient's values and preferences in clinical practice guidelines. Patient Preference Adherence. 2018;12:2309–23. https://doi.org/10.2147/ppa.S177540.
- Espitalier F, Fanous A, Aviv J, Bassiouny S, Desuter G, Nerurkar N, Postma G, Crevier-Buchman L. International consensus (ICON) on assessment of oropharyngeal dysphagia. Eur Ann Otorhinolaryngol Head Neck Dis. 2018;135(1s):S17–21. https:// doi.org/10.1016/j.anorl.2017.12.009.
- Yamamoto T, Ikeda K, Usui H, Miyamoto M, Murata M. Validation of the Japanese translation of the Swallowing Disturbance Questionnaire in Parkinson's disease patients. Qual Life Res. 2012;21(7):1299–303. https://doi.org/10.1007/s1113 6-011-0041-2.

- Schindler A, Mozzanica F, Monzani A, Ceriani E, Atac M, Jukic-Peladic N, Venturini C, Orlandoni P. Reliability and validity of the Italian Eating Assessment Tool. Ann Otol Rhinol Laryngol. 2013;122(11):717–24. https://doi.org/10.1177/000348941312201 109.
- Sales DS, Alvarenga RM, Vasconcelos CC, Silva RG, Thuler LC. Translation, cross-cultural adaptation and validation of the Portuguese version of the DYMUS questionnaire for the assessment of dysphagia in multiple sclerosis. Springerplus. 2013;2:332. https ://doi.org/10.1186/2193-1801-2-332.
- Oda C, Yamamoto T, Fukumoto Y, Nakayama K, Sato M, Murata M, Kobayashi Y. Validation of the Japanese translation of the Dysphagia Handicap Index. Patient Preference Adherence. 2017;11:193–8. https://doi.org/10.2147/ppa.s126052.
- Moller R, Safa S, Ostberg P. Validation of the Swedish translation of eating assessment tool (S-EAT-10). Acta Otolaryngol. 2016;136(7):749–53. https://doi.org/10.3109/00016 489.2016.1146411.
- Magalhaes Junior HV, Pernambuco Lde A, Souza LB, Ferreira MA, Lima KC. Translation and cross-cultural adaptation of the Northwestern Dysphagia Patient Check Sheet to Brazilian Portuguese. Codas. 2013;25(4):369–74.
- Lin LC, Chen MY, Chen YC, Portwood MJ. Psychometrics of a Chinese translation of the swallowing questionnaire. J Adv Nurs. 2001;34(3):296–303.
- Kwon CH, Kim YH, Park JH, Oh BM, Han TR. Validity and reliability of the korean version of the MD anderson Dysphagia inventory for head and neck cancer patients. Ann Rehabil Med. 2013;37(4):479–87. https://doi.org/10.5535/arm.2013.37.4.479.
- Hajdu SF, Plaschke CC, Johansen C, Dalton SO, Wessel I. Crosscultural translation, adaptation and reliability of the Danish M. D. Andeson Dysphagia Inventory (MDADI) in patients with head and neck cancer. Dysphagia. 2017;32(4):472–9. https://doi. org/10.1007/s00455-017-9785-3.
- Goncalves MI, Remaili CB, Behlau M. Cross-cultural adaptation of the Brazilian version of the Eating Assessment Tool—EAT-10. Codas. 2013;25(6):601–4. https://doi.org/10.1590/s2317-17822 013.05000012.
- Ginocchio D, Alfonsi E, Mozzanica F, Accornero AR, Bergonzoni A, Chiarello G, De Luca N, Farneti D, Marilia S, Calcagno P, Turroni V, Schindler A. Cross-cultural adaptation and validation of the Italian version of SWAL-QOL. Dysphagia. 2016;31(5):626– 34. https://doi.org/10.1007/s00455-016-9720-z.
- Farahat M, Malki KH, Mesallam TA, Bukhari M, Alharethy S. Development of the Arabic Version of Dysphagia Handicap Index (DHI). Dysphagia. 2014;29(4):459–67. https://doi.org/10.1007/ s00455-014-9528-7.
- Carlsson S, Ryden A, Rudberg I, Bove M, Bergquist H, Finizia C. Validation of the Swedish M. D. Anderson Dysphagia Inventory (MDADI) in patients with head and neck cancer and neurologic swallowing disturbances. Dysphagia. 2012;27(3):361–9. https:// doi.org/10.1007/s00455-011-9375-8.
- Burgos R, Sarto B, Segurola H, Romagosa A, Puiggros C, Vazquez C, Cardenas G, Barcons N, Araujo K, Perez-Portabella C. Translation and validation of the Spanish version of the EAT-10 (Eating Assessment Tool-10) for the screening of dysphagia. Nutr Hosp. 2012;27(6):2048–54. https://doi.org/10.3305/ nh.2012.27.6.6100.
- Bauer F, Seiss M, Grassel E, Stelzle F, Klotz M, Rosanowski F. Swallowing-related quality of life in oral cavity cancer. The German version of the Anderson Dysphagia Inventory. Hno. 2010;58(7):692–7. https://doi.org/10.1007/s00106-010-2117-7.
- Barzegar-Bafrooei E, Bakhtiary J, Khatoonabadi AR, Fatehi F, Maroufizadeh S, Fathali M. Validation of the Persian version of the dysphagia handicap index in patients with neurological disorders. Iran J Neurol. 2016;15(3):128–32.

- 35. Woisard V, Bodin S, Puech M. The Voice Handicap Index: impact of the translation in French on the validation. Rev Laryngol Otol Rhinol (Bord). 2004;125(5):307–12.
- Speyer R, Cordier R, Kertscher B, Heijnen BJ. Psychometric properties of questionnaires on functional health status in oropharyngeal dysphagia: a systematic literature review. Biomed Res Int. 2014;2014:458678. https://doi.org/10.1155/2014/45867 8.
- 37. Dwivedi RC, St Rose S, Chisholm EJ, Georgalas C, Bisase B, Amen F, Kerawala CJ, Clarke PM, Nutting CM, Rhys-Evans PH, Harrington KJ, Kazi R. Evaluation of swallowing by Sydney Swallow Questionnaire (SSQ) in oral and oropharyngeal cancer patients treated with primary surgery. Dysphagia. 2012;27(4):491–7. https://doi.org/10.1007/s00455-012-9395-z.
- Shaker R, Belafsky PC, Postma GN, Easterling C, SpringerLink (Online service) (2013) Principles of Deglutition A Multidisciplinary Text for Swallowing and its Disorders.
- 39. Holland G, Jayasekeran V, Pendleton N, Horan M, Jones M, Hamdy S. Prevalence and symptom profiling of oro-pharyngeal dysphagia in a community dwelling of an elderly population: a self-reporting questionnaire survey. Dis Esophagus. 2011;24(7):476–80. https://doi.org/10.111 1/j.1442-2050.2011.01182.x.
- Nimmons D, Michou E, Jones M, Pendleton N, Horan M, Hamdy S. A longitudinal study of symptoms of oropharyngeal Dysphagia in an elderly community-dwelling population. Dysphagia. 2016;31(4):560–6. https://doi.org/10.1007/s00455-016-9715-9.
- Archer SK, Garrod R, Hart N, Miller S. Dysphagia in Duchenne muscular dystrophy assessed by validated questionnaire. Int J Lang Commun Disord. 2013;48(2):240–6. https://doi.org/10.11 11/j.1460-6984.2012.00197.x.
- Szczesniak MM, Maclean J, Zhang T, Liu R, Cook IJ. The normative range for and age and gender effects on the Sydney Swallow Questionnaire (SSQ). Dysphagia. 2014;29(5):535–8. https://doi. org/10.1007/s00455-014-9541-x.
- 43. Quon H, Hui X, Cheng Z, Robertson S, Peng L, Bowers M, Moore J, Choflet A, Thompson A, Muse M, Kiess A, Page B, Fakhry C, Gourin C, O'Hare J, Graham P, Szczesniak M, Maclean J, Cook I, McNutt T. Quantitative evaluation of head and neck cancer treatment-related Dysphagia in the development of a personalized treatment deintensification paradigm. Int J Radiat Oncol Biol Phys. 2017;99(5):1271–8. https://doi.org/10.1016/j.ijrob p.2017.08.004.
- Arenaz Bua B, Bulow M. Validation in Swedish of Sydney swallow questionnaire. BMC Res Notes. 2014;7:742. https://doi. org/10.1186/1756-0500-7-742.
- Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine. 2000;25(24):3186–91.
- Logemann JA. Screening, diagnosis, and management of neurogenic dysphagia. Semin Neurol. 1996;16(4):319–27. https://doi. org/10.1055/s-2008-1040990.
- Rosenbek JC, Robbins JA, Roecker EB, Coyle JL, Wood JL. A penetration-aspiration scale. Dysphagia. 1996;11(2):93–8.
- Robbins J, Coyle J, Rosenbek J, Roecker E, Wood J. Differentiation of normal and abnormal airway protection during swallowing using the penetration-aspiration scale. Dysphagia. 1999;14(4):228–32. https://doi.org/10.1007/pl00009610.
- O'Neil KH, Purdy M, Falk J, Gallo L. The Dysphagia outcome and severity scale. Dysphagia. 1999;14(3):139–45. https://doi. org/10.1007/p100009595.
- Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, Bouter LM, de Vet HC. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol. 2007;60(1):34–42. https://doi.org/10.1016/j.jclin epi.2006.03.012.

- Koo TK, Li MY. A guideline of selecting and reporting intraclass correlation coefficients for reliability research. J Chiropr Med. 2016;15(2):155–63. https://doi.org/10.1016/j.jcm.2016.02.012.
- McGraw K, Wong SP. Forming inferences about some intraclass correlation coefficients. Psychol Methods. 1996;1:30. https://doi. org/10.1037/1082-989x.1.1.30.
- Bland JM, Altman DG. Statistical methods for assessing agreement between two methods of clinical measurement. Lancet. 1986;1(8476):307–10.
- Hajian-Tilaki K. Receiver Operating Characteristic (ROC) curve analysis for medical diagnostic test evaluation. Caspian J Intern Med. 2013;4(2):627–35.
- McHorney CA, Tarlov AR. Individual-patient monitoring in clinical practice: are available health status surveys adequate? Qual Life Res. 1995;4(4):293–307.
- Manjaly JG, Vaughan-Shaw PG, Dale OT, Tyler S, Corlett JC, Frost RA. Cricopharyngeal dilatation for the long-term treatment

of dysphagia in oculopharyngeal muscular dystrophy. Dysphagia. 2012;27(2):216–20. https://doi.org/10.1007/s00455-011-9356-y.

- Mossey-Gaston CHP, Oscroft N. The Relationship between patient perception and swallow function in patients with ataxia-telangiectasia—a pilot study. J Oral Health Dent Proc UKSRG-2016. 2017;1:A0017.
- Schwartz B, Martin SW. 1—Principles of Epidemiology and Public Health A2—Long, Sarah S. In: Principles and practice of pediatric infectious diseases. 4 h ed. Content Repository Only!, London, pp 1–9. (2012). https://doi.org/10.1016/B978-1-4377-2702-9.00003-9.
- Bel S. Temps de préparation et durée des repas. In: WIV-ISP (ed) Enquête de consommation alimentaire 2014–2015. Rapport 1. WIV-ISP, Bruxelles; (2015).