



Development of a Dutch Version of the Sydney Swallow Questionnaire: Assessing Oropharyngeal Dysphagia Severity in Dutch-Speaking Populations

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Abstract

Aims The oropharyngeal dysphagia (OD) poses substantial health risks and affects quality of life. Patient-reported outcome measures (PROMs) are gaining prominence for their crucial role in early detection and adapting rehabilitation and management decisions. This highlights the need for culturally pertinent versions in different languages, especially when addressing conditions like OD. This study aimed to translate, culturally adapt, and assess the test-retest reliability of the Sydney Swallow Questionnaire (SSQ), a PROM designed to detect the risk of OD, for Dutch-speaking populations.

Materials and Methods The SSQ was translated and adapted based on Beaton's guidelines. Validity and test-retest reliability were assessed in 100 healthy participants, with a subset of 30 participants assessed over a 15-day interval. Intra-class correlation coefficient (ICC) values were calculated to determine test-retest reliability.

Results The SSQ-Dutch was well received and well understood, with a median total score of 65.5/1700. Notably, 95% of participants scored below the established dysphagia risk cut-off, consistent with previous validations. The 15-day interval ICC for the SSQ-Dutch total scores was 0.82 (CI 95%: 0.66–0.91), indicating good reliability. While most questions had moderate-to-good reliability, five showed slightly lower ICC.

Conclusion The SSQ-Dutch emerges as a validated and reliable tool for assessing OD risk in Dutch-speaking individuals. Future studies should evaluate its efficacy in symptomatic populations and consider cultural variations in Dutch-speaking regions.

Keywords Oropharyngeal dysphagia · Assessment · Sydney Swallow Questionnaire · Swallowing · Questionnaire

Introduction

The oropharyngeal dysphagia (OD) can have significant consequences such as aspiration, pneumonia, and malnutrition, leading to increased morbidity and mortality [1–3]. Additionally, beyond the direct health implications, OD has also important psychological and social consequences. It notably contributes to a diminished well-being, reduced quality of life, increased caregiver burden, elevated healthcare costs, and extended hospital stay [4–11]. Appropriate management, which includes early detection, optimal clinical evaluation, and adapted follow-up, is a key element in minimizing OD-related complications [1, 12, 13]. Various tools are available for OD assessment, and healthcare professionals have to choose the one adapted to the specific situation, but also in regard to their characteristics, strengths, limitations, psychometric properties, or diagnostic measurements

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[1]. Non-instrumental tools are often used in the initial stage of swallowing assessment, playing a crucial role in identifying individuals at risk of OD and referring them for further diagnosis (typically using instrumental tools) and necessary treatment, if needed [14]. These screening tools offer some advantages, including being non-invasive, low risk, cost-effective, easy to interpret, and not too time-consuming [15]. Many of these tools also have the advantage to require little or no special training to administer [16, 17]. In this perspective, Speyer et al. highlighted the growing importance that the patient-reported outcome measures (PROMs) have gained in assessing OD over recent years. Indeed, these PROMs play a crucial role in patient-centred healthcare and can improve communication, patient engagement, and self-efficacy as patients may be more involved in goal setting [17, 18]. The Sydney Swallow Questionnaire (SSQ), developed by Wallace et al., is a specifically designed tool to detect the risk of OD and has been already used in various populations of adult patients [19–24]. It has been validated in English, Swedish, French, German, and Turkish, and its psychometric properties make it an ideal screening tool for OD assessment [15, 19, 25–27]. Previous studies, initiated by Szsceniak et al., have proposed different cut off scores, ranging from 111.0 to 755.0/1700 [19, 21, 22, 25, 27–29]. As highlighted by Atar et al., the variations in these scores are attributed to the comparison tools used in the validation process (in the absence of a gold standard), cultural differences and authors' choice regarding the couple sensitivity/specificity [27].

Currently, no Dutch version of the SSQ is available. As already mentioned in the previous studies that translated and validated other dysphagia assessment tools such as EAT-10, the M.D. Anderson Dysphagia Inventory (MDADI) and the Swallowing Quality-of-Life Questionnaire (DSWAL-QoL) into Dutch, it seems important and useful to validate a Dutch version of the SSQ [30–33]. This will enable the assessment of the risk of OD in Dutch-speaking populations and allow healthcare professionals to tailor their assessment and management strategies more effectively. Therefore, the aim of this study is to translate and cross-culturally adapt the SSQ for Dutch-speaking populations and evaluate its validity and test-retest reliability in healthy subjects.

Methods

This study was carried out in two parts: (1) Dutch translation of the original SSQ and cross-cultural adaptation of the translated version of the SSQ, and (2) Evaluation of the validity and the test-retest reliability of the SSQ-Dutch (SSQ-D) in healthy Belgian Dutch-speaking volunteers. The SSQ is composed 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 includes instructions asking participants to place an “X” across the scale to indicate the degree of difficulty they were experiencing related to each item [28]. The distance in millimeters from the origin of the VAS corresponds to a score from 0 to 100 for each question. Only question 12 is scored between 0 and 5 based on duration of an average meal. This score is multiplied by 20 to achieve a score between 0 and 100 [19]. Finally, the total score of the questionnaire is calculated by summing up each question scores. The higher the score, the more severe the risk of OD. Average completion time is approximately five minutes [19, 34]. If a patient does not complete at least 15 out of the 17 questions, the questionnaire is excluded from further analysis. If a patient omitted one or two questions, an estimated score for each omitted question is calculated, based on the total score divided by the total possible score for the questions answered [15].

Part 1: Translation and Cross-Cultural Adaptation

The formal approval from the lead author of the SSQ was requested and obtained [19]. The back-translation and the cross-cultural adaptation were performed based on Beaton's guidelines [35]. In stage 1, two native Dutch translators (Translation) translated the original version of the SSQ from Australian English to Dutch independently. One of them had a medical background (speech and language therapist), the second was a professional translator without medical notions. In stage 2, both versions were compared after consensus on the divergences in translations (*Synthesis*). In stage 3, the SSQ was translated back into English by an independent native English speaker, who did not participate in the first or second stage (*Back-translation*). Then, 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 10 Dutch-speaking people (*Pretesting*).

Part 2: Evaluation of the Validity and the Test-Retest Reliability of the SSQ-Dutch

Participants

Study was approved by the local Medical Ethics Committee (B403201628760). Healthy volunteers from different groups were recruited: non-medical staff, caregivers, university students, and residents of multi-residence housing

facilities. The recruitment took place in Brussels and the Dutch-speaking part of Belgium between February 1, 2018, and July 31, 2018. Participation was on a voluntary basis and without financial compensation. Participants signed a written informed consent form in accordance with the Declaration of Helsinki and the current guidelines for Clinical Good Practice. Inclusion criteria were to speak and read Dutch as a first language, and be aged between 18 and 80 years. Exclusion criteria included inability to complete the questionnaire, any documented swallowing difficulties or dysphagia-related, as well as unstable or quickly progressive disease.

Protocol

The protocol included two phases. During the first one (evaluation of the validity), one hundred healthy participants were recruited. After obtaining their consent, they were given oral explanations about the study and were asked to self-complete the SSQ-D (SSQ-D1). The cut-off score of 234/1700 was used to evaluate the validity, as established by Szczesniak et al. (2014) [29]. Thirty participants of the first phase were randomly recruited to examine the test-retest reliability in the second phase. After completing the questionnaire, each of them received a package containing a second SSQ-D (SSQ-D2) along with a prepaid envelope. They were asked to fill out the SSQ-D2 after two weeks at home 15 days later to evaluate the test-retest reliability of the questionnaire.

Statistical/Data Analysis

Statistical analysis was performed using IBM SPSS 27.0 for Windows. Descriptive statistics were computed for demographic parameters, and the Kolmogorov-Smirnov test was used to check for normality of the data. Based on normality, data were expressed as mean $\pm$ standard deviation or median and interquartile range. Test-retest reliability was measured using a two-way mixed effect, absolute agreement, single rater/measurement intra-class correlation coefficient (ICC). An ICC with a value of 0.50–0.75 indicating moderate reliability, 0.75–0.90 indicating good reliability, and above 0.90 indicating excellent reliability [36]. All ICC were expressed by absolute value and 95% confidence interval.

Results

Part 1

After completion of the back-translation and cross-cultural adaptation, the Dutch version of the SSQ was considered

understandable and acceptable by the expert committee. During the process, formulations and examples related to food consistency in the Dutch questionnaire were adapted according to the comments of the experts and the pilot group. For Q2, the expert committee included ‘water’ as an example of thin liquids, which seems like an obvious and fundamental choice. For Q3, the word “custard” was culturally adapted which they translated with “vla”. The expert committee made some modifications to Q4 too, they added two typical Belgian nourishments in the examples of soft food; “appelmoes” (apple puree) and “zachte kaas” (soft cheese). For Q8, they adapted the sentence to be more understandable for all people and they added between brackets “speeksel of voedsel” (saliva or food). After some reflexion they adapted Q14 by adding more specifically which area should be emptied (Mond en keel helemaal leegmaken i.e. mouth and throat emptied). For Q17, “belemmeren” was replaced by “invloed hebben op” because the word “belemmeren” was found to have a negative connotation in Dutch. Concerning the meaning of the word “ever” in Q9–Q11 and in Q14 and Q15, the expert committee hesitated how to translate it because the word “ever” has a very wide interpretation. It was pointed out by three subjects of our prefinal version as “once in your life” and thus “Everyone chokes once in their life, right?” Eventually they translated it into “ooit” which keeps exactly the same signification as in the original questionnaire.

All control participants completed the SSQ-D without assistance. The time required to fill out the questionnaire never exceeded five minutes and rating did not last more than three minutes. The SSQ-D is available in Supplement 1.

Part 2

The SSQ-D, obtained by back-translation and cross-cultural adaptation, was administered to 100 healthy subjects (54 M/46F, mean age = 51.2 ± 15.6 years). All the subjects considered the SSQ-D understandable. Median SSQ-D total score was 65.5/1700 (82.0) (Table 1). During Part 2, we considered that the SSQ-D was understood and well accepted as reflected by the lack of omitted questions and no need for assistance to complete it. The time required to fill out the questionnaire never exceeded five minutes and rating did not last more than three minutes. 95% of the subjects had a SSQ-D total score below the cut-off of 234, indicating that they were not at risk of dysphagia. The ICC for the SSQ-D total scores filled in with an interval of 15 days was 0.82 (CI 95%: 0.66–0.91) (Table 2). Questions 6 (difficulty to swallow dry food) and 12 (time to eat) had an excellent reliability. Five questions had an ICC < 0.50, namely Q2 (difficulty to swallow thin liquids), Q11 (coughing with liquids), Q14 (more than one swallow), Q15 (regurgitation and coughing

Table 1 Results and calculated measurements of SSQ-D

Scores	Median	IQR
Question 1	0.0	3.0
Question 2	0.0	2.0
Question 3	0.0	2.0
Question 4	0.0	2.0
Question 5	2.0	5.0
Question 6	2.0	6.0
Question 7	0.0	3.0
Question 8	0.0	3.0
Question 9	2.0	8.0
Question 10	5.5	18.0
Question 11	5.0	14.0
Question 12	20.0	0.0
Question 13	0.0	2.0
Question 14	2.0	7.0
Question 15	2.0	4.0
Question 16	0.0	3.0
Question 17	0.0	2.0
Total	65.5	82.0

SSQ-D, Dutch Version of the Sydney Swallow Questionnaire; IQR, Interquartile range

during meals) and Q16 (severity of dysphagia). Other questions indicated moderate to good reliability.

Discussion

The aim of this study was to translate the SSQ into Dutch, culturally adapt it, and subsequently evaluate its test-retest reliability. Based on the results, the translation and

cultural adaptation for Dutch-speaking patients were found to be comprehensible by all involved parties, including the expert committee, pilot group, and healthy subjects. This translation is an important step to assess the risk of OD in Dutch-speaking patients while the use of a PROM may be limited by patients who experience language comprehension deficits.

95% of the healthy subjects scored below the cut-off on the SSQ-D, aligning with the specificity percentages previously observed for various the cut-off scores [15, 22, 27]. The median SSQ-D total score was 65.5/1700, widely under the cut-off score. It aligns with those from prior SSQ validation studies on healthy subjects. It is important to highlight that this study did not validate a specific cut-off for the Dutch version. We opted for the cut-off originally described by Szczesniak et al. for healthy subjects [29]. It would be beneficial to define a version-specific cut-off, especially when using the SSQ-D with patients. Regarding test-retest reliability, the ICC for the SSQ-D total score was good, and most of the questions demonstrated acceptable test-retest reliability.

While our study contributes valuable insights, it is important to acknowledge and address certain limitations. Only thirty patients were included in the test-retest. This small sample size might have influenced the ICC values for items, which could differ with a larger sample. Additionally, reliability results may be influenced by the use of the ICC rather than the Pearson correlation coefficient. However, this method is advantageous because, unlike the Pearson correlation coefficient which can overestimate true relationships,

Table 2 Properties of SSQ-D1 and SSQ-D2 in healthy subjects

Questions	SSQ-D1		SSQ-D2		ICC	CI 95%
	Mdn	IQR	Mdn	IQR		
1	1	2	2	3	0.75	0.53-0.87
2	0	2	2	3	0.40	0.06-0.66
3	0	2	2	3	0.83	0.67-0.92
4	1	2	2	3	0.84	0.70-0.92
5	2	3	2.5	5	0.78	0.59-0.89
6	2	4	2.5	4	0.92	0.84-0.96
7	0	3	2	3	0.87	0.74-0.93
8	2	3	2	3	0.54	0.22-0.75
9	3	6	2.5	5	0.70	0.46-0.84
10	5.5	13	4	9	0.51	0.18-0.73
11	3	14	3.5	7	0.19	0.15-0.50
12	20	0	20	0	0.94	0.89-0.97
13	2	3	2	4	0.72	0.49-0.86
14	2.5	9	3	5	0.24	0.14-0.55
15	2	6	3	5	0.44	0.09-0.69
16	1	2	2	4	0.42	0.08-0.67
17	0	2	2	4	0.75	0.52-0.87
Total	78.5	64	71	60	0.82	0.66-0.91

SSQ-D1, Dutch Version of the Sydney Swallow Questionnaire filled in at the first appointment; SSQ-D2, Dutch Version of the Sydney Swallow Questionnaire filled in after two weeks; IQR, Interquartile range; ICC, Intra-class correlation; CI, Confidence interval

the ICC tends to be more conservative, especially with smaller samples [37]. Moreover, the purpose of the SSQ is exploratory rather than diagnostics. Thus, a low ICC for certain questions scores is not concerning, unlike if this low value was for the overall score, which is not the case here. In comparison to a prior study, that assessed ICC of the SSQ, our results for the total score fell within the range reported in the previous validation [15, 25, 27]. On the other hand, the two-week time interval was considered long enough to avoid participants to recall their previous answers while at the same time, short enough to minimize the probability of changes of clinical state but there is no standard rule on the matter of time between test and retest. The original SSQ validation study for the English version of the tool described that the total score was stable in 12 ± 2 -day intervals [19]. The French and the Turkish version used a 15-day interval, and the Swedish version, a 3-week interval [15, 25, 27].

Finally, even if the examiner orally ensured the subjects' comprehension, we did not conduct a standard cognitive assessment on the participants, such as the Mini-Mental State Examination. As a result, we cannot definitively determine whether a question's misunderstanding stems from cognitive impairment or from a flawed translation or cultural adaptation. However, none of the previous SSQ validations have performed this assessment either.

The results indicated that Q12, related to meal times, demonstrated the highest ICC and the lowest IQR. Intriguingly, Q12 seldom received a zero rating, with 65% of healthy subjects scoring 20. This is consistent with Belgian national statistics, where average meal durations reported in a federal study were 14, 21, and 26 min for breakfast, lunch, and dinner, respectively [38]. This aligns with findings from Audag et al. regarding the French-speaking validation. In their study, a mealtime duration of 15 to 30 min was typical for healthy controls [15].

Significantly, this study focuses on the application of SSQ-D among healthy subjects, contributing valuable insights into the questionnaire's performance within this population. Future investigations could extend the validation to include symptomatic subjects, thereby broadening the scope of applicability. Moreover, our translation validation was conducted with subjects residing in the Dutch-speaking part of Belgium, comprising approximately 6.5 million individuals. To enhance the generalizability of our findings, potential cultural differences or vocabulary adaptations should be examined in other Dutch-speaking regions or countries (e.g. The Netherlands, Suriname, etc.).

Conclusions

In today's patient-centered healthcare landscape, patient-reported outcome measures stand as essential pillars. The SSQ-Dutch has been validated and is a reliable tool for evaluating the risk of oropharyngeal dysphagia among Dutch-speaking subjects. It is paramount to further probe its psychometric properties in real-world clinical settings.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s12070-024-04484-3>.

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

Declarations

Conflicts of Interest/Competing Interests The authors have no relevant financial or non-financial conflicts of interest to declare.

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