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ORIGINAL ARTICLE

The Validation and Psychometric Properties of the Dutch Version of the Swallowing Quality-of-Life Questionnaire (DSWAL-QOL)

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Abstract The aim of this work was to evaluate the psychometric properties of the Dutch version of the Swallowing Quality-of-Life Questionnaire (DSWAL-QOL). A cross-sectional survey of 295 dysphagic patients and 124 healthy controls was studied to evaluate the validity and reliability of the DSWAL-QOL, and 50 patients were recruited for the test–retest reliability. Construct validity was validated through principal component analysis and a correlation study between the DSWAL-QOL and the SF-36. The psychometric properties of the DSWAL-QOL were found to be largely similar to those of the original SWAL-QOL, except the Sleep scale; the composite Symptoms score reaffirms its validity in this study. The DSWAL-QOL was able to differentiate between dysphagic and nondysphagic patients and is sensitive to disease severity as measured by known-groups validity, based on different food and liquid textures. The DSWAL-QOL is a clinically valid and reliable tool for assessing the quality of life in Dutch-speaking dysphagic patients, regardless of the cause or severity of the dysphagia.

Keywords Dysphagia · Quality of life · Psychometrics · Outcome measurements · Deglutition · Deglutition disorders

During the past decades the necessity of considering health-related quality of life (HR-QOL) has increased as research consistently demonstrated the correlation between QOL and clinical end points to be weak [1–5]. The acknowledgment of HR-QOL as an important measurement of treatment effectiveness is reflected in the health-care “value compass,” which is increasingly accepted as a useful framework for conceptualizing and measuring health outcomes [6]. The compass includes four outcomes: (1) clinical status, such as mortality, morbidity, and pathophysiology; (2) health-care costs and utilization; (3) quality of life, including function and well-being; and (4) patient satisfaction. Many clinical specialties have developed their own disease-specific quality-of-life and quality-of-care outcomes tools [7–12], accumulating to over 160 different measures to assess HR-QOL in the early 1990 s [13].

The most common and convenient way to assess patient-reported outcome (PRO) is a self-report instrument as it is less time-consuming than interviews, guarantees that questions are asked in a standardized manner, and facilitates comparisons within and between groups [14]. Self-report instruments can also be used in clinical practice for estimation of symptoms or treatment effects, helping patients communicate their problems and helping health-care professionals to identify major concerns of patients.

Because of the social function of eating and drinking, dysphagia can adversely affect an individual’s mental and physical health. The need for a dysphagia-specific PRO led to the development of the Swallowing Quality of Life

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questionnaire (SWAL-QOL) by McHorney et al. in 2000 [15, 16]. The authors defined quality of life as an overall state of well-being that is a composite of (1) the ability to fulfill usual and desired physical, role, and social activities; (2) the psychological effectiveness with which one performs usual and desired activities; (3) satisfaction with health-care services related to dysphagia treatment; and (4) dysphagia symptom status. The questionnaire is constructed using multi-item scales to elicit information about each domain of health outcomes, since they have superior content validity to single-item measures and also achieve higher standards of reliability, especially when studying relatively small samples, common in dysphagia research [17–19]. The SWAL-QOL has shown good psychometric qualities [20], an absolute condition to be clinically relevant [21]. It can therefore be considered the gold standard in dysphagia research regarding QOL issues. However, the psychometric evaluation of any questionnaire is a never-ending process and as such is always inferred, never established [22]. Additional evidence about the reliability, validity, and responsiveness of the SWAL-QOL can be gathered by its use in different patient groups with varying dysphagia severity. The aim of this study was to translate the SWAL-QOL into Dutch (DSWAL-QOL) and study its psychometric characteristics in order to provide a valid and reliable tool for assessing patients' perspectives of dysphagia in Dutch-speaking countries.

Materials and Methods

The Original SWAL-QOL

The SWAL-QOL consists of 44 items, grouped into 10 subscales. The minimum and maximum scores per subscale indicate an extremely impaired quality of life (score of 0) versus no impairment (score of 100) as experienced by the individual. The questionnaire is designed to assess eight concepts of dysphagia related to quality of life, including General burden, Eating duration, Eating desire, Food selection, Communication, Fear of eating, Social functioning, and Mental health, and two concepts of generic quality of life, namely, Sleep and Fatigue. There is also a symptom-frequency scale in which each of 14 items is scored from 1 to 5. It has been suggested that this scale on clinical symptoms can be represented in a single Symptoms score, bringing the total of subscales to 11 [23].

Cross-cultural Adaptation Processes of the SWAL-QOL

The original SWAL-QOL was translated into the Dutch language according to the five-step cross-cultural adaptation process of translation and back-translation as described in international guidelines [13, 24]. The professionals involved were fluently bilingual, with either English or Dutch as their native language. Each item was translated into Dutch by an ENT surgeon and two speech-language pathologists, all of them with extensive experience in dysphagia management (1: forward translation). To ensure the unanimity and the interpretation of the translated manuscript, it was passed on to two other speech-language pathologists, also considerably experienced in dysphagia, and any conceptual issues were discussed until agreement was achieved (2: synthesis). Two professional interpreters, both members of the European Union of Associations of Translation Companies, performed the back-translation to English independently (3: backward translation). These back-translations were compared to the original manuscript and items of incongruent translation were noted. These items were again translated into Dutch by two different Flemish speech-language pathologists, both translations were compared, and agreement was reached after discussion. Another native English speaker translated these final items once more to English. Finally, the back-translation of every item was semantically identical to the original English manuscript (4: expert panel). The translated instrument (DSWAL-QOL) was tested to ensure that each item and the available responses were understood by and felt acceptable to the test patients (5: pilot study).

The Short Form-36 (SF-36)

The SF-36 is a multipurpose, short-form health survey with only 36 questions. It yields an 8-scale profile of functional health and well-being scores as well as psychometrically based physical and mental health summary measures. The SF-36 is a generic measure and, accordingly, it has proven useful in surveys of general populations and has been translated in more than 50 countries as part of the International Quality of Life Assessment (IQOLA) Project. The eight domains are Physical Functioning (PF), Role limitations due to Physical problems (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role limitations due to Emotional problems (RE), Mental Health (MH), and a single question concerning perceived health during the last year. The Belgian version of SF-36 has established reliability and validity [25] so it was used to test the convergent and divergent validities of the DSWAL-QOL in this study.

Subject Recruitment

Cases

A nonexperimental cross-sectional survey was adopted using several defined patient groups. Convenience sampling was used to recruit subjects from an outpatient clinic (in a university hospital and a private practice) and a residential care setting for the elderly from March 2008 to April 2011. The inclusion criteria were (1) neurological or mechanical oropharyngeal dysphagia diagnosed by a speech-language pathologist and/or an ENT surgeon using a clinical swallowing evaluation with objectivation through fiber-optic endoscopic evaluation of swallowing (FEES) or videofluoroscopic evaluation of swallowing (VFES), and (2) unchanged level of dysphagia during at least 4–6 weeks according to the patient, caregivers, and the medical file. Exclusion criteria were (1) inability to understand written (or spoken) Dutch, (2) evidence of purely esophageal dysphagia, (3) denial of dysphagia by the patient despite the objective swallowing studies, and (4) suspicion of dementia as screened by the Mini-Mental State Examination. Any assistance required in completing the questionnaire was documented. Fifty patients were selected at random to complete the questionnaire a second time, at an average of 2 weeks later, to allow the determination of test–retest reliability [26]. These 50 patients also completed the additional Short Form-36 questionnaire (SF-36) to allow the determination of convergent and divergent validities.

Healthy Controls

We also recruited a total of 124 healthy male and female subjects between the ages of 22 and 89 years as control subjects to test the ability of the DSWAL-QOL to differentiate between those with and without dysphagia. The control group was recruited from the general community, speech-language pathologists attending a dysphagia course, and the staff of a long-term residential care facility. During an interview none of these people reported suffering from prior or existing medical conditions and/or using medications with potential influence on oropharyngeal motor performance or sensation. An oropharyngeal motor exam revealed normal structures and function of the bulbar musculature for all subjects. No objective swallowing study was performed.

Data Analysis

The statistical analysis was performed using SPSS 19.0 (IBM, SPSS, Inc., Chicago, IL, USA). Measurement properties were compared to the quality criteria as proposed by Terwee et al. [21].

Content validity examines the extent to which the concepts of interest are comprehensively represented by the items in the questionnaire [27]. Relevant concepts can be defined in terms of symptoms (physical, psychological, and social), functioning, general health perceptions, or overall quality of life [28]. Ideally, these different outcome levels should clearly be distinguished and measured by separate subscales. Since the content validity of the SWAL-QOL items is very well established [15, 16], a similar content validity of the DSWAL-QOL was assumed.

Construct validity evaluates whether a questionnaire actually measures the intended construct(s). We examined construct validity by convergent, discriminant, and known-groups validity. Convergent validity demonstrates whether a questionnaire correlates with other instruments to which it should be related, whereas discriminant validity refers to constructs that theoretically should be unrelated. For convergent and discriminant validities, correlations were calculated using Spearman's nonparametric correlation coefficient (r_s). A strong correlation was considered to be over 0.70, a moderate correlation between 0.30 and 0.70, and a weak correlation below 0.30 [29, 30]. Known-groups validity refers to whether an instrument can differentiate between groups of patients whose health status differs, in this case patients with versus those without dysphagia, and between patients with different levels of severity of dysphagia (as judged by dietary restrictions).

Factor analysis is a technique for identifying groups of interrelated variables within a large data set, i.e., identifying the latent construct of the data set. This technique allows a better understanding of the structure of a set of variables by explaining the maximum amount of common variance by using the smallest number of explanatory constructs. Principal component analysis (PCA) is a factor analysis technique where the sample used is the study population so results cannot be extrapolated beyond that particular sample. Generalization of the results can be achieved only if analysis using different samples reveals a similar factor structure. The correlation matrix of the data set should be worthy of factor analysis by using Bartlett's test of sphericity [31]. The adequacy of the sample size to obtain a stable factor solution should be evaluated using the Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy [31]. After extraction of the constructs using PCA, the correct number of factors should be determined preferably by parallel analysis [32]. If subsequent oblique rotation reveals a correlated factor structure, then the orthogonally rotated solution should be discarded.

The reliability of a scale indicates how free it is from random error. Two frequently used indicators of a scale's reliability are internal consistency and test–retest reliability (also referred to as "temporal stability"). Floor or ceiling effects are considered to be present if more than 15 % of respondents achieved the lowest or highest possible score, respectively [21, 33]. Internal consistency as measured by Cronbach's α is a measure of the extent to which items in a questionnaire (sub)scale are correlated (i.e., homogeneous), thus measuring the same concept. A low Cronbach's α

($\leq$0.70) indicates a lack of correlation between the items in a scale, which makes summarizing the items unjustified. A very high Cronbach's α (>0.90) indicates high correlations among the items in the scale and possible redundancy of one or more items. Alpha values of $\geq$0.70 are usually judged as indicative of good internal consistency and satisfactory for group-level research, while higher values of $\geq$0.80 are recommended or necessary for individual-patient decision-taking [18, 29, 34, 35]. Two measures were used to evaluate the test–retest reliability of the DSWAL-QOL. Spearman's rho correlation coefficient (r_s) was used to estimate the test–retest reliability, since normality was not obtained in a small sample of 50 pairs. The intraclass correlation coefficient (two-way random-effects model for agreement, ICC(A,1) [36]) is preferred and was also used to estimate the test–retest reliability. A positive rating for reliability can be given only when the ICC is at least 0.70 in a sample size of at least 50 patients [18].

We used known-groups validity to test the clinical validity of the DSWAL-QOL [37]. To be useful in clinical applications, measures of patient-based health outcomes should meet two clinical validity standards: (1) discriminate between groups with and without disease and (2) distinguish between severity levels of a given condition. This test requires the construction of mutually exclusive groups that differ in swallowing status based on external clinical criteria, e.g., tube-feeding or dietary level. Independent *t*-tests were used when comparing two opposing groups, and significance levels were determined observing Levene's test for equality of variances. Comparing three opposing groups was done using ANOVA. If significance was reached on Levene's test, the significance level of the ANOVA was evaluated using the robust test of equality of means (Welch). Post-hoc analyses were assessed using the Games-Howell test, accounting for the violation of the assumption of similar population variances [22, 37, 38].

Results

Patient Characteristics

Of 343 patients, 295 met the inclusion and exclusion criteria. The successful recruitment rate was 86 %. Of these subjects, 27 (9.15 %) had one or more missing items in the questionnaire and their results were not included in the final analysis. Therefore, the analysis was conducted on 268 patients who completed the entire research procedure. Reasons for the dysphagia were typical for those with oropharyngeal dysphagia (e.g., head and neck cancer, cerebrovascular disorders, and degenerative neurological disorders). Their demographic information is presented in Table 1.

Features of Score Distributions

The normal distribution of the data from the subscales, analyzed using the Kolmogorov-Smirnov and the Shapiro-Wilk test, indicate that all subscales deviate significantly from a normal distribution (df = 268, $p < 0.000$), and the coefficients of skewness were all negative, indicating few low values. The full range of 0–100 score distribution was, however, observed for all scales, with mean scores for all of the scales ranging from 57.57 to 79.36 (Table 2). The score distribution (Table 3) clearly shows the presence of multiple ceiling effects (Food selection, Social functioning, Eating desire, Mental health, Fear of eating, General burden, Communication, and Eating duration). No floor effects were present.

Factor Analysis

Prior to performing PCA, the suitability of the data for factor analysis was assessed. Inspection of the correlation matrix revealed the presence of a high number of coefficients with values of 0.3 and above. The Kaiser-Meyer-Olkin value was 0.894, exceeding the recommended value of 0.6, and Bartlett's test of sphericity reached statistical significance (p =0.000), supporting the factorability of the correlation matrix. Principal components analysis, according to the Kaiser criterion, revealed the presence of ten components with eigenvalues exceeding 1. The number of components to be retained for further investigation was elucidated by the results of parallel analysis, which showed only six components with eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size (44 variables × 268 respondents). To aid in the interpretation of these six components, oblique rotation (Direct Oblimin) was selected due to the presence of several correlations greater than 0.3. The pattern matrix is represented in Table 4. The six-component solution explained a total of 63.52 % of the variance (Table 5).

The items that cluster on the same components can be described as follows. Component 1 is centered on the eating and feeding process proper [having an appetite, choosing suitable foods, experiencing the meal-time burden (including trouble chewing food), and confronting the excessive eating duration]. Component 2 reflects generic health factors (fatigue and sleep) not specific to dysphagia. Component 3 is a symptom cluster, grouping almost all probed symptoms experienced by dysphagic patients (except chewing and excess saliva). Component 4 deals with problems in the important social aspects of swallowing. Component 5 groups communication issues and the symptom of having excess saliva, which clearly can aggravate probable preexisting communication difficulties

Table 1 Descriptive characteristics of participants

Characteristic	Study group ($n = 268$)		Control group ($n = 124$)	
	N	%	*N*	%
Age (years)				
20–30	0	0	64	51.6
31–40	2	.7	4	3.2
41–50	32	11.9	20	16.1
51–60	27	10.1	26	21.0
61–70	98	36.6	2	1.6
71–80	52	19.4	4	3.2
≥81	57	21.3	4	3.2
Mean (SD)	67.80	(12.12)	39.96	(16.69)
Gender				
Male	177	66.0	63	49.2
Female	91	34.0	61	50.8
Etiology			n/a	n/a
Head and neck cancer	134	50.0		
Stroke	62	23.1		
Parkinson's disease	55	20.5		
Zenker's diverticulum	17	6.3		
Mode of feeding				
Nonoral	7	2.6	0	0
Oral	261	97.4	124	100
Pleasure	24	9.0	0	0
Pureed	38	14.2	0	0
Soft	84	31.3	22	17.7
Normal	115	42.9	102	82.3
Mode of drinking				
Nonoral/ice chips	10	3.7	0	0
Oral	258	96.3	124	100
Pudding	6	2.2	0	0
Honey	9	3.4	0	0
Nectar	23	8.6	7	5.6
Normal	220	82.1	117	94.4
Place of living				
Home	229	85.4	117	94.4
Residential care	39	14.6	7	5.6
Marriage status				
Single	17	6.3	35	28.2
Married	184	68.7	59	47.6
Cohabiting	12	4.5	10	8.1
Divorced	39	14.6	14	11.3
Widowed	16	6.0	6	4.8
Facilitation required to complete the questionnaire				
No	142	53	115	92.7
Yes	126	47	9	7.3
Read questions	75	28	7	5.6
Read questions, wrote answers	51	19	2	1.7

n/a not applicable

Table 2 Features of score distribution

Subscale	No. items	Min	Max	Mean	SD	Coefficient of skewness	P_{25}	P_{50}	P_{75}
General burden	2	0	100	63.89	33.88	−0.531	38.0	75.0	100.0
Eating duration	2	0	100	57.57	33.73	−0.231	25.0	63.0	88.0
Eating desire	3	0	100	72.18	28.29	−0.815	50.0	75.0	100.0
Symptoms	14	0	100	72.34	18.50	−0.636	61.0	75.0	84.0
Food selection	2	0	100	79.22	27.04	−1.325	63.0	88.0	100.0
Communication	2	0	100	63.88	28.19	−0.370	50.0	63.0	88.0
Fear of eating	4	0	100	79.36	20.91	−1.104	69.0	81.0	100.0
Social functioning	5	0	100	77.15	28.06	−1.238	65.0	85.0	100.0
Mental health	5	0	100	76.87	24.66	−0.915	60.0	85.0	100.0
Sleep	2	0	100	64.13	23.34	−0.549	63.0	75.0	88.0
Fatigue	3	0	100	64.13	23.35	−0.549	50.0	67.0	83.0

P percentile

Table 3 Floor and ceiling effects

Scales	Floor[a]	Ceiling[b]
General burden	9.3	29.5[c]
Eating duration	10.1	22.8[c]
Eating desire	3.0	31.3[c]
Symptoms	0.0	9.7
Food selection	3.0	47.4[c]
Communication	3.4	23.1[c]
Fear of eating	0.4	29.5[c]
Social functioning	3.4	39.2[c]
Mental health	0.0	31.0[c]
Sleep	1.1	13.8
Fatigue	1.1	10.1

[a] Floor score = 0; values expressed as %

[b] Ceiling score = 100; values expressed as %

[c] Effect present

(especially in our study population with a high percentage of cancer and stroke). Finally, component 6 clusters around psychological well-being, combining fear and mental health.

Reliability

Cronbach's α coefficients on the DSWAL-QOL ranged from 0.501 to 0.952 on the 11 subscales (Table 6). Only one scale (Sleep, $\alpha = 0.501$) failed to reach the reliability standard of 0.70 recommended for group-level research. The Fear of eating subscale showed that the α level could be raised from 0.791 to 0.800 by deleting the item "never know when going to choke"; the small gain in α, however, does not justify deleting the item. Otherwise, five scales had an α coefficient from 0.791 to 0.880, and five scales even had $\alpha > 0.90$. In general, the items in the 11 scales could be considered homogeneous and thus measuring the same traits in each scale, respectively.

In 2-week retest reliability, all scales showed a significant level of correlation. Spearman's rho ranged from 0.52 to 0.90 ($p = 0.000$), with a median of 0.78, meaning the DSWAL-QOL in general demonstrated good short-term stability. The average ICC were higher than those of Spearman's rho, ranging from 0.504 to 0.912 ($p = 0.000$), with a median of 0.794 (mean = 0.787), meaning the agreement within raters was high [21]. All results were significant. The ICC summary of the reliability estimates is presented in Table 6.

Construct Validity

The moderate correlations between Mental health, Social functioning, and Fatigue subscales in both questionnaires show agreement on the same general (not dysphagia-specific) constructs, indicating convergent validity of the DSWAL-QOL (Table 7). Weak correlations between General burden, Food selection, and Eating duration and all SF-36 domains indicate that both questionnaires are measuring two related but different constructs. These findings support the hypothesis that there is a small overlap between the two quality-of-life questionnaires but that the DSWAL-QOL measures a more specific construct compared to the general SF-36.

Clinical Validity

Dysphagic Patients Versus Normal Swallowers

Table 8 presents the results of clinical validity for each individual DSWAL-QOL subscale between dysphagic patients and normal swallowers using independent *t*-tests. As hypothesized, dysphagic patients scored statistically

Table 4 Pattern matrix

Item	Scale	Components					
		1	2	3	4	5	6
Rarely hungry	Eating desire	*0.803*					
Don't enjoy	Eating desire	*0.693*					
Don't care if eat	Eating desire	*0.684*					
Figure can-can't eat	Food selection	*0.652*					
Major distraction	Burden	*0.645*					
Difficult dealing	Burden	*0.643*					
Longer time	Eating duration	*0.561*					
Takes forever	Eating duration	*0.535*					
Difficult find food	Food selection	*0.533*					
Problem chewing	Symptom	*0.519*		0.405			
Feel tired	Fatigue		*0.777*				
Fall asleep	Sleep		*0.775*				
Feel weak	Fatigue		*0.766*				
Feel exhausted	Fatigue		*0.759*				
Trouble staying asleep	Sleep		*0.746*				
Drooling	Symptoms			*0.705*			
Dribble from mouth	Symptoms			*0.669*			
Choke on food	Symptoms			*0.638*			
Food stick mouth	Symptoms			*0.626*			
Choke on liquid	Symptoms			*0.579*			
Cough – food stuck	Symptoms			*0.570*			
Gagging	Symptoms			*0.551*	0.322		
Coughing	Symptoms			*0.528*		0.321	
Clear throat	Symptoms			*0.476*			
Food stick throat	Symptoms	0.408		*0.465*			
Dribble from nose	Symptoms			*0.460*			0.323
Thick saliva, phlegm	Symptoms			*0.328*			
Role change	Social functioning				*0.859*		
Dislike social gathering	Social functioning				*0.814*		
Change work activity	Social functioning				*0.812*		
Hard social life	Social functioning				*0.777*		
Don't go out	Social functioning				*0.691*		
Hard speaking clear	Communication					*0.845*	
Hard understand me	Communication					*0.823*	
Excess saliva, phlegm	Symptoms			0.388		*0.502*	
Afraid pneumonia	Fear					*0.460*	0.301
Choking foods	Fear						*0.652*
Frustrated	Mental health						*0.609*
Depressed	Mental health				0.357		*0.602*
Afraid choking liquids	Fear						*0.601*
Impatient dealing	Mental health						*0.581*
Discouraged	Mental health	0.379					*0.564*
Never know when choke	Fear						*0.551*
So careful annoy	Mental health	0.393					*0.479*

Extraction method = principal component analysis; rotation method = Oblimin with Kaiser normalization; values <0.3 are omitted

[a] Rotation converged in 14 iterations

Italic identifies items loading predominantly on a specific component

Table 5 Total variance explained

Component	Total variance explained					
	Initial eigenvalues			Rotation sums of squared loadings		
	Total	% of variance	Cumulative %	Total	% of variance	Cumulative %
1	16.720	38	38	6.523	14.824	14.824
2	3.038	6.904	44.903	6.004	13.645	28.470
3	2.984	6.781	51.684	5.088	11.563	40.033
4	1.919	4.362	56.046	4.102	9.323	49.356
5	1.744	3.963	60.009	3.716	8.446	57.802
6	1.546	3.513	63.522	2.517	5.720	63.522

Table 6 Reliability estimates

SWAL-QOL	Internal consistency[a]	Test–retest[b]			
	(Cronbach's α)	Spearman's rho	Sig.[c]	ICC[d]	Sig.[c]
General burden	0.952	0.813	0.000	0.794	0.000
Eating duration	0.880	0.727	0.000	0.752	0.000
Eating desire	0.821	0.834	0.000	0.885	0.000
Symptoms	0.903	0.517	0.000	0.504	0.000
Food selection	0.812	0.760	0.000	0.805	0.000
Communication	0.920	0.717	0.000	0.749	0.000
Fear of eating	0.791 (0.800)[e]	0.740	0.000	0.784	0.000
Social functioning	0.933	0.901	0.000	0.912	0.000
Mental health	0.947	0.784	0.000	0.786	0.000
Sleep	0.501	0.821	0.000	0.869	0.000
Fatigue	0.869	0.793	0.000	0.822	0.000

[a] Internal-consistency sample size $N = 268$

[b] Test–retest sample size $N = 50$; average test–retest interval = 14 days

[c] Correlation is significant at the 0.01 level (2-tailed)

[d] Two-way random-effects model, absolute agreement

[e] The number in parenthesis is Cronbach's α adjusted with one item deleted

significantly lower (i.e., worse QOL) on all of the scales. The effect sizes (expressed as η^2) are all large, with a mean of 0.37 and ranging from 0.24 (Fatigue) to 0.50 (Sleep). The greatest differences were observed for Sleep, Symptoms, and General burden.

Dysphagic Patients with Oral Nutrition Versus Nonoral Feeding (Tube Feeding)

To construct the known groups, patients on an oral diet were contrasted with a nonoral feeding group composed of patients who were on tube-feeding ($n = 7$) and patients who were predominantly tube fed but who were allowed minimal amounts of "pleasure feeding" ($n = 24$). The independent *t*-test indicated that patients with nonoral feeding experienced statistically significantly lower (worse) QOL than patients on an oral diet on several subscales of the DSWAL-QOL (Table 9). Eight of the 11 tests involving tube-feeding status were significant at the 0.01 level. The largest differences observed between tube-feeders and regular eaters were for Mental health, Symptoms, Social functioning, Eating duration, and General burden.

Dysphagic Patients Differing in Food Texture of Oral Diet

Differences in DSWAL-QOL scores in patients with different levels of oral diet (normal, soft, or pureed consistency) were calculated using a one-way ANOVA. In all subscales there is a statistically significant difference between normal diet and soft or pureed diet (Tables 10, 11). These data confirm the hypothesis that increasing dysphagia severity, as reflected by food texture, is associated with worsening QOL. The scores for patients on pureed diets are particularly low.

Table 7 Construct validity: DSWAL-QOL versus SF-36 (Spearman's rho)

DSWAL-QOL	PF	RP	BP	GH	VT	SF	RE	MH
General burden	0.16[a]	0.25[a]	0.25[b]	0.29[a]	0.34[b]	0.31[b]	0.07	0.19
Eating duration	0.03	0.02	0.05	0.11	0.14	0.31[a]	0.09	0.18
Eating desire	0.31[a]	0.33[a]	0.25[a]	0.24[a]	0.41[b]	0.51[b]	0.31[a]	0.15[b]
Symptoms	0.37[a]	0.39[b]	0.33[a]	0.36[b]	0.22[a]	0.31[a]	0.10	0.16[a]
Food selection	0.09	0.15	0.09	0.07	0.16	0.09	0.13	0.02
Communication	0.15[a]	0.24[a]	0.22[a]	0.22[a]	0.14	0.39[b]	0.34[b]	0.23[a]
Fear of eating	0.48[b]	0.37[a]	0.35[b]	0.49[b]	0.31[a]	0.22[a]	0.17	0.24[b]
Social functioning	0.22[b]	0.43[b]	0.39[b]	0.34[a]	0.35[b]	0.65[a]	0.26[a]	0.43[b]
Mental health	0.28[a]	0.13[a]	0.39[a]	0.43[a]	0.34[a]	0.47[b]	0.11	0.38[b]
Sleep	0.17[a]	0.22[a]	0.33[a]	0.35[b]	0.36[a]	0.30[a]	0.11	0.23[a]
Fatigue	0.53[a]	0.42[a]	0.39[a]	0.52[b]	0.62[b]	0.51[b]	0.08[a]	0.31[b]

[a] Significant at 0.01 level (2-tailed)

[b] Significant at 0.05 level (2-tailed)

Dysphagic Patients Differing in Liquid Consistency

Three subscales (Sleep, Fatigue, and Communication) demonstrated no significant differences in the DSWAL-QOL scores among the groups that differed in the consistency of their liquids (Table 12). In all other subscales, patients drinking thin liquids had better QOL than patients on either thickened or NPO/ice chips diet. Patients on NPO/ice chips demonstrated additional loss of QOL compared to patients on thickened liquids in the domains of Symptoms, Mental health, and Social functioning (Table 13).

Discussion

A comprehensive evaluation of dysphagia should include not only some physiological measures to assess bolus

Table 8 Differences between dysphagic group and control group

Subscale	Dysphagic group (n = 268)		Control group (n = 124)		Mean diff.	Sig. (2-tailed)	η^2
	Mean	SD	Mean	SD			
General burden	57.80	32.96	95.29	11.76	37.49	<0.000	0.408
Eating duration	55.48	33.29	91.44	17.08	35.96	<0.000	0.338
Eating desire	71.25	28.20	95.66	7.20	24.41	<0.000	0.311
Symptoms	67.63	22.32	94.98	5.25	27.35	<0.000	0.479
Food selection	66.33	29.38	96.30	10.55	29.97	<0.000	0.358
Communication	63.88	28.19	94.15	9.56	30.27	<0.000	0.389
Fear of eating	74.12	24.42	96.37	7.42	22.25	<0.000	0.322
Social functioning	70.35	31.70	99.64	1.93	29.29	<0.000	0.367
Mental health	72.57	26.46	98.79	4.43	26.22	<0.000	0.389
Sleep	69.23	20.84	97.36	6.89	28.13	<0.000	0.503
Fatigue	64.13	23.35	84.94	13.53	20.81	<0.000	0.240

Table 9 Differences between oral diet and nonoral diet

Subscale	Nonoral diet (n = 31)		Oral diet (n = 237)		Mean diff.	Sig. (2-tailed)	η^2
	Mean	SD	Mean	SD			
General burden	29.16	23.87	61.54	32.17	32.38	<0.000	0.148
Eating duration	26.00	19.94	59.34	32.78	33.34	<0.000	0.194
Eating desire	54.13	25.88	73.49	27.77	19.36	<0.000	0.054
Symptoms	42.16	17.46	70.96	20.71	28.80	<0.000	0.195
Food selection	47.35	25.14	68.81	29.03	21.46	<0.000	0.067
Communication	60.19	28.37	64.36	28.20	4.17	0.440	0.002
Fear of eating	50.03	24.48	77.27	22.63	27.24	<0.000	0.115
Social functioning	36.77	24.03	74.75	29.94	37.98	<0.000	0.195
Mental health	42.90	15.48	76.46	25.11	33.56	<0.000	0.289
Sleep	62.35	24.86	70.13	20.15	7.78	0.051	0.010
Fatigue	58.29	25.87	64.89	22.94	6.60	0.139	0.006

Table 10 Dysphagic patients differing in food texture

Subscale	Normal diet ($n = 115$)		Soft diet ($n = 84$)		Pureed diet ($n = 38$)		Sig.	η^2
	Mean	SD	Mean	SD	Mean	SD		
General burden	79.23	25.60	49.46	30.10	34.71	22.49	<0.000	0.310
Eating duration	77.99	25.24	46.89	30.78	30.39	21.72	<0.000	0.335
Eating desire	84.44	21.47	66.82	28.80	55.05	28.57	<0.000	0.167
Symptoms	82.83	12.75	67.43	15.74	42.84	19.99	<0.000	0.468
Food selection	86.29	18.41	54.51	28.19	47.53	25.91	<0.000	0.349
Communication	73.17	25.68	57.4	27.22	53.11	29.94	<0.000	0.095
Fear of eating	89.17	12.41	76.10	19.63	43.87	18.41	<0.000	0.486
Social functioning	90.87	18.18	71.79	27.68	32.50	17.85	<0.000	0.466
Mental health	91.3	13.59	71.85	22.97	41.71	17.21	<0.000	0.491
Sleep	75.64	18.81	66.82	21.07	60.74	17.14	<0.000	0.081
Fatigue	72.90	21.04	60.21	23.07	51.03	18.83	<0.000	0.133

Table 11 Post-hoc Games–Howell test for differences in food texture

Subscale	Post-hoc Games–Howell test		
	Normal-Soft	Normal-Pureed	Soft-Pureed
General burden	<0.000	<0.000	0.009
Eating duration	<0.000	<0.000	0.003
Eating desire	<0.000	<0.000	0.097
Symptoms	<0.000	<0.000	<0.000
Food selection	<0.000	<0.000	0.377
Communication	<0.000	0.001	0.732
Fear of eating	<0.000	<0.000	<0.000
Social functioning	<0.000	<0.000	<0.000
Mental health	<0.000	<0.000	<0.000
Sleep	0.007	<0.000	0.216
Fatigue	<0.000	<0.000	0.058

transport and airway protection (VFES and/or FEES), but also the patient's perspective using a PRO. There is a clear need to use validated, disease-specific questionnaires in the patient's own language and reflective of their culture. Therefore, the psychometric properties of the DSWAL-QOL were evaluated in this study using data from patients with varying etiologies and severity levels of oropharyngeal dysphagia and comparing them with a control group without dysphagia.

A large group of dysphagic patients was questioned using the DSWAL-QOL. Obviously, the convenience sampling in this study may not fully represent the total population of patients with oropharyngeal dysphagia. Nevertheless, the study group did manifest many symptoms of dysphagia and their QOL scores were widely spread and considerably lower compared to the control group, which, with respect to psychometric evaluations,

Table 12 Dysphagic patients differing in liquid consistency

Subscale	Thin ($n = 220$)		Thickened ($n = 38$)		NPO/ice chips ($n = 10$)		Sig.	η^2
	Mean	SD	Mean	SD	Mean	SD		
General burden	61.51	32.45	44.21	30.34	27.70	26.41	<0.000	0.066
Eating duration	59.48	33.08	39.34	28.65	28.90	24.51	<0.000	0.069
Eating desire	73.67	28.04	61.68	28.30	54.30	18.18	0.004	0.036
Symptoms	70.95	21.32	57.34	17.85	33.80	20.70	<0.000	0.134
Food selection	68.66	29.69	56.42	27.51	52.60	17.39	0.008	0.030
Communication	64.50	28.45	60.00	27.43	65.00	26.87	0.657	0.003
Fear of eating	76.86	23.11	64.39	26.89	50.70	23.07	0.002	0.067
Social functioning	74.41	29.90	56.97	34.00	32.00	22.63	<0.000	0.094
Mental health	75.80	25.49	61.97	27.57	42.00	8.23	<0.000	0.085
Sleep	70.31	19.89	65.63	25.25	59.10	21.10	0.192	0.015
Fatigue	65.37	22.67	59.16	26.05	55.80	25.63	0.249	0.014

NPO nil per os

Table 13 Post-hoc Games–Howell test for differences in liquid consistency

Subscale	Post-hoc Games–Howell test		
	Thin-thickened	Thin-NPO/ ice chips	Thickened-NPO/ ice chips
General burden	0.006	0.007	0.235
Eating duration	0.001	0.008	0.495
Eating desire	0.050	0.021	0.582
Symptoms	<0.000	0.001	0.015
Food selection	0.040	0.045	0.853
Communication	0.625	0.998	0.862
Fear of eating	0.026	0.015	0.269
Social functioning	0.016	<0.000	0.030
Mental health	0.016	<0.000	0.001
Sleep	0.528	0.273	0.273
Fatigue	0.358	0.502	0.929

suggests a representative sample of the dysphagic population. When comparing our results to the original study [20], some differences were observed. These might be explained by the different proportions of etiology (H&N cancer 50 vs. 28 %, stroke 15.8 vs. 23 %, neurodegenerative 12.7 vs. 20 %). Our patient sample was also more impaired when defined by food texture of oral intake, with 43 % eating regular food in our study compared with 64 % in the American study, and 14 % on pureed diets compared to 6 %. Liquid diet status was comparable. A remaining limitation in the application of the SWAL-QOL or its current available translations is the absence of sufficient data on tube-fed patients. In our study only 2.6 % of patients were exclusively tube-fed, with an additional 9 % taking only minimal oral "pleasure feeding," meaning that our sample could be not representative for this subgroup, as in the original study [20].

The DSWAL-QOL was well accepted by patients, although half of the patients needed some help to complete the questionnaire. In general, responses covered the full range of scores, with no floor effects. Multiple ceiling effects were present in the patient group despite the high percentage of more severely impaired patients, possibly reflecting a state of solace that some eating possibilities remained despite the fact that the dysphagia was the result of life-threatening diseases such as cancer or stroke. We did not study the time span between the onset of dysphagia and DSWAL-QOL scores, nor did we conduct additional psychological evaluation to probe these feelings of survivorship, although both have a considerable and different impact [39, 40].

Construct validity was established by conducting principal components analysis. Six distinctive components were found in the DSWAL-QOL instead of the intended "dichotomy" of the original SWAL-QOL in a dysphagia-specific QOL factor and more generic health factor. Component 1 concerns eating and feeding and the daily hardships dysphagic patients must endure. Component 2 reflects the generic health factor found in the original SWAL-QOL. Component 3 combines almost all symptom-related questions, supporting the reliability data for its use as a separate Symptoms scale [23, 41]. Components 4 and 5 describe social functioning and communication, while component 6 groups psychological well-being. Our findings clearly show that the original subscales remain grouped as clusters but may be further combined thereby achieving a more compact description of the swallowing-related QOL. Further work will be needed to investigate its usefulness. When restricting the PCA model to obtain just two components, the original structure of a dysphagia-specific and a general component [20] were retrieved (data available upon request).

Assessment of internal consistency showed that only one of the subscales (Sleep) of the DSWAL-QOL did not reach an internal consistency of 0.70 or higher as recommended for group-level research, in accordance with the original SWAL-QOL data [20]. Five subscales had α levels between 0.80 and 0.90, suitable for group level analysis (Eating desire, Eating duration, Food selection, Fear of eating, and Fatigue), and the remaining five had α levels greater than 0.90, approaching levels suitable for individual comparison (General burden, Communication, Mental health, Social functioning, and Symptom score). Nevertheless, to reach the final version of the DSWAL-QOL, we chose to include the Sleep subscale and the complete Fear of eating subscale to allow easier international comparisons; clinicians using the DSWAL-QOL, however, should be wary of putting too much confidence in the generic Sleep subscale, and to a lesser extent the Fear of eating subscale.

There are two possible explanations for the weak internal consistency of the Sleep scale. The number of items drives Cronbach's α values, and the subscale Sleep includes only two items; this might contribute to the lower value of Cronbach's α. Second, the prevalence of severe insomnia in the general Belgian population ranges from 4 to 22 % [42]. This leads to one of the highest usage levels of hypnosedative drugs in Europe, up to 31 % in a unselected sample of hospitalized patients [43]. The main reason for prescription of these drugs in hospital was to continue the use of hypnosedative drugs taken at home [44]. This could easily confound our findings since we did not control for the use of hypnosedative drugs.

The Symptom score [23, 41] had an internal consistency of 0.903, which further supports its use as a separate subscale on a group to individual level. It allows clinical researchers and practitioners to represent a variety of clinical symptoms in one severity score. Further study of its value in characterizing aspects of QOL in different etiologies of oropharyngeal dysphagia is needed however.

Test–retest reliability was calculated with a 2-week interval in an at-random subgroup of patients. Both Spearman's rho and intraclass correlations demonstrated good and significant short-term stability in all subscales.

When comparing different translations of the SWAL-QOL, some differences can be observed. The data by Bogaardt [23] show the reliability of a Symptoms score, reaffirmed by our data, which was not documented in the original questionnaire [20] or the Chinese version [45]. The Eating desire and Communication scales of Bogaardt, however, fell short of the recommended α levels, which was not a problem in our study. The Chinese translation also found the Eating desire scale to be a weakness and the Food selection scale was no more than sufficient, both probably the result of language and cultural differences. In the Swedish version [41], the subscales of Eating duration and Sleep marginally failed to reach acceptable α levels. The Sleep scale of the DSWAL-QOL was shown to be less than reliable.

The weak correlations between the DSWAL-QOL and SF-36 on dysphagia-related constructs indicate that these questionnaires effectively measure different constructs, indicating discriminant validity. Convergent validity with moderate correlations was demonstrated on more generic constructs. The DSWAL-QOL is the more specific questionnaire when assessing dysphagic patients, reaffirming its gold standard status.

The known-groups validity and clinical validity of all subscales of the DSWAL-QOL were demonstrated, with significant differentiation between normal swallowers and dysphagic patients with large effect sizes. The clear differentiation between oral feeders versus tube feeders on the dysphagia-specific subscales provides additional validity support. The DSWAL-QOL is also sensitive to dysphagia severity, when contrasting both food texture diets and liquid-consistency diets. We fully agree with McHorney et al. [20] that even for severely dysphagic patients, a permanent diet restriction to pureed consistencies should be "a last resort" when all other treatment modalities have been exhausted. Liquid-consistency diets did not differ in the generic DSWAL-QOL scales; eating-related scales, however, did demonstrate clear differences between diet types, similar to the findings with food texture.

Conclusion

The DSWAL-QOL demonstrates sound psychometric values to allow its use in daily clinical settings and/or research. The Sleep subscale, however, shows insufficient psychometric strength and careful interpretation is needed. Our results confirm that QOL is significantly reduced in subjects with oropharyngeal dysphagia of different etiologies and severities. Comprehensive psychometric evaluation is needed before using questionnaires in a different patient group or culture.

Conflict of interest The authors have no conflicts of interest to disclose.

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