Measurement and clinical evaluation of oropharyngeal dysphagia; a multidimensional approach

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Quality of life in oncological patients with oropharyngeal dysphagia: Validity and reliability of the Dutch version of the Deglutition Handicap Index (DHI) and the MD Anderson Dysphagia Inventory (MDADI)

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ABSTRACT

Quality of life is considered to be an important outcome measurement in objectifying the current health status or therapy effects in patients with oropharyngeal dysphagia. In this study, the validity and reliability of the Dutch version of the Deglutition Handicap Index (DHI) and the MD Anderson Dysphagia Inventory (MDADI) have been determined in oncological patients with oropharyngeal dysphagia. 76 consecutive patients were selected at the Medical University Hospital Maastricht and were asked to fill in three questionnaires on quality of life related to oropharyngeal dysphagia (the Swal-Qol, the MDADI, and the DHI) and a simple one-item visual analogue Dysphagia Severity Scale. None of the quality of life questionnaires showed any floor or ceiling effects. The test retest reliability of the MDADI and the Dysphagia Severity Scale proved to be good. The test retest reliability of the DHI could not be determined because of insufficient data. However, the intraclass correlation coefficients were rather high. The internal consistency proved to be good. However, when applying confirmatory factor analysis, the underlying constructs as defined by the subscales per questionnaire could not be distinguished. When considering the criterion validity, the MDADI as well as the DHI showed satisfactory associations with the Swal-Qol (reference or gold standard) after having removed its less relevant subscales.

INTRODUCTION

Patients with advanced head and neck cancer often suffer from oropharyngeal dysphagia as a result of the disease itself or its treatment[1]. Dysphagia can lead to malnutrition and dehydration as well as an increased risk of aspiration[2]. When objectifying a patient's current health status as well as the effects of a therapeutic intervention, quality of life is considered to be an important evaluation tool[3].

In the literature, a few questionnaires on health related quality of life can be found that focus on oropharyngeal dysphagia: The Swal-Qol[4], the MD Anderson Dysphagia Inventory (MDADI)[5], and the Deglutition Handicap Index (DHI)[6]. When using a questionnaire in research, its psychometric characteristics must be well-known and of sufficient high quality, otherwise, the study results cannot be interpreted or be given any clinical relevance. Although the reliability and validity of the Swal-Qol has been described[4], hardly any data are available on the psychometric quality of the MDADI or the DHI. The Swal-Qol is an elaborated 44-item questionnaire containing eleven subscales. Although the Swal-Qol is a commonly used instrument in research, its application in daily clinical practice may be limited. Clinicians need a short, easy-to-handle questionnaire for clinical screening.

In this study, the validity and the reliability of the Dutch version of the DHI and the MDADI in oncological patients with oropharyngeal dysphagia will be determined.

METHODS

Subjects

Patients were selected consecutively at the outpatients' clinic for dysphagia at the Department of Otorhinolaryngology, Head and Neck Surgery and at the MAASTRO clinic at the Medical University Hospital in Maastricht (MUMC). Patient recruitment took place during outpatients' visits at the outward patient clinic. A small sample of included patient was recruited by phone after having studied their medical records. All included patients had to meet the following criterion; the patients had to be diagnosed by a laryngologist as having oropharyngeal dysphagia based on oncological disorders. Furthermore, a patient's general condition had to be considered as stable during repeated measurements. Lastly, included patients may not show any cognitive restrictions. Patients received oral information about the study and were only included after informed consent.

In total, 76 patients were included in the study. There were 57 (75%) men and 19 (25%) women in this study, with an age ranging from 45 to 83 years. The mean age for men

and women was, respectively, 64 and 61. The status of the oral feeding restrictions was scored, using the Functional Oral Intake Scale or FOIS by Crary et al.[7]. Two subjects were tube dependent, while all other subjects were on a total oral diet varying from a diet with a single consistency (N=7), with multiple consistencies and special preparation or compensation (N=30), without any special preparation but with some food limitations (N=28), to a normal oral diet (N=9).

Questionnaires

Four questionnaires have been used in this study; Three questionnaires on quality of life related to oropharyngeal dysphagia, namely, the Swal-Qol[4], the MD Anderson Dysphagia Inventory (MDADI)[5], the Deglutition Handicap Index (DHI)[6], plus a simple one-item visual analogue scale (Dysphagia Severity Scale). Both the MDADI and the DHI were translated into Dutch by three independent researchers and combined into one final translation by mutual consensus. The Dysphagia Severity Scale needed no translation and the Swal-Qol had already been translated by Bogaardt et al.[8].

The first questionnaire, the Swal-Qol, is considered to be the golden standard for determining quality of life in oropharyngeal dysphagia. This 44-item tool exhibits good internal-consistency reliability and short-term reproducibility[4]. It consists of eleven subscales (see Table 1). The minimum and maximum score per subscale are zero and 100, indicating extremely impaired quality of life versus no impairment as experienced by the individual. The DHI is a 30-item questionnaire on deglutition related aspects in daily life (5 point-rating scale: 0-4). The questionnaire is subdivided in three domains of ten items: emotional (psychosocial consequences), functional (nutritional and respiratory consequences) and, physical (symptoms related to swallowing), The minimum score is zero points (indicating no handicap) and the maximum score is 120 points (indicating maximum handicap)[6]. The MDADI consists of 20 items. It is composed of a global assessment (a single question) and three subscales, namely, the emotional subscale (eight items), the functional subscale (five items), and the physical subscale (six items). The global assessment refers to the individual's swallowing difficulty affecting the overall daily routine. The emotional, functional, and physical subscales refer to the individual's affective response to the swallowing disorder, the impact of the disorder on daily activities, and the self-perceptions of the swallowing difficulties, respectively[5]. Using five-point scales (1-5), the minimum total score is 20 and the maximum total score is 100. In the original version of the MDADI, all but two items were scored in a way that higher scores referred to higher functioning. In the Dutch translation, it was decided to use a uniform way of scoring. Thus, by adjusting the scoring of two items, low scores refer to low functioning, whereas high scores refer to high functioning. The Dysphagia Severity Scale is a self-designed evaluation tool,

Table 1. Descriptive analysis of the MD Anderson Dysphagia Inventory (MDADI), the Deglutition Handicap Index (DHI), the Dysphagia Severity Scale, and the Swal-Qol.

Quality of Life Scale		Range of Scale	Median (25';75' percentiles)	N
Swal Qol[a]	Burden	0 – 100	63 (6;75)	73
	Food Selection	0 – 100	75 (25;88)	71
	Eating Duration	0 – 100	25 (0;63)	71
	Eating Desire	0 – 100	75 (27;100)	72
	Fear	0 – 100	88 (69;100)	71
	Sleep	0 – 100	75 (44;88)	73
	Fatigue	0 – 100	58 (33;83)	73
	Communication	0 – 100	63 (50;88)	71
	Mental Health	0 – 100	65 (30;90)	71
	Social Functioning	0 – 100	65 (25;92)	73
	Symptoms	0 – 100	63 (44;77)	73
DHI[b]	Total Score	0 – 120	36 (20;46)	42
	Emotional Subscore	0 – 40	10 (2;22)	46
	Functional Subscore	0 – 40	12 (8;19)	44
	Physical Subscore	0 – 40	10 (6;16)	44
MDADI[a,c]	Total Score	20 – 100[2]	66 (51;77)	74
	Global Assessment	1 – 5	4 (2;4)	76
	Emotional Subscore	6 – 30	20 (15;25)	75
	Functional Subscore	5 – 25	17 (13;21)	75
	Physical Subscore	8 – 40	25 (19;29)	75
Dysphagia Severity Scale[a]		0 – 100	49 (34;71)	57

[a] Lower scores indicate more severely impaired quality of life or ability to swallow (MDADI, Dysphagia Severity Scale, Swal-Qol). [b] Higher scores indicate more severely impaired quality of life (DHI). [c] According to Chen et al. (2001) the range of scores is zero to 100, while using a scale of 1 to 5. In this study the range of scores has been adjusted.

consisting of one visual analogue scale, quantifying the severity of the swallowing disorder and the extent of impairment experienced by the patient. A score of 100 (the maximum) indicates normal swallowing abilities, while a score of zero indicates extreme swallowing impairment or inability to swallow.

Protocol

Patients were asked to fill in all four questionnaires during their outpatients' visit or when recruited by phone, at home. Within two weeks after the first measurement[9], all patients received by post the MDADI, the DHI and the Dysphagia Severity Scale for repeated measurements purposes. The researchers made sure that all repeated

measurements were sent back in time for adequate retest interval analysis[9], reminding patients if necessary by phone.

Statistical analysis

Table 2 presents a glossary of psychometric and statistical terminology as used in this study. Measurement properties of the MDADI and the DHI were determined and compared to the quality criteria as defined by Terwee et al.[10].

Firstly, both questionnaires were examined for possible **floor and ceiling effects** by objectifying the number of respondents achieving the lowest or highest possible scores. Next, the **test retest reliability** was assessed by determining intraclass correlations coefficients (two-way random effects model, ICC) between repeated measurements on the MDADI, the DHI and the Dysphagia Severity Scale. Confirmatory Maximum Likelihood (ML) factor analyses were performed to determine the number of (homogeneous) (sub)scales of each questionnaire. In addition, by computing Cronbach's α coefficients, the **internal consistency reliability** of the MDADI and the DHI was estimated. The associations among the four administered questionnaires plus the FOIS, and among the subscales per instrument have been determined by nonparametric Spearman's correlation coefficients. (Sub)scales from the MDADI and the DHI that were supposed to measure the same concept were compared, thus, defining **construct validity** (**convergent validity**). Finally, the **criterion validity** was determined by computing nonparametric Spearman's correlations between the Swal-Qol (reference or gold standard) and both the MDADI and the DHI. All statistical analyses were performed using SPSS 15.0.

RESULTS

Table 1 presents the descriptive statistics for all four questionnaires. To examine possible **floor or ceiling effects**, the total score of the MDADI, the total score of the DHI, and the Dysphagia Severity Scale have been visualized by means of histograms (Figure 1A, 1B, and 1C), thus, objectifying the number of respondents achieving the lowest or highest possible scores. As less than 15% of the respondents achieved the lowest or highest possible score, no floor or ceiling effects are considered to be present[10].

To assess the **test retest reliability**, intraclass correlation coefficients (two-way random effects model, ICC) have been determined between repeated measurements on the total scores of the MDADI and the DHI, as well as on the Dysphagia Severity Scale. The ICC's were respectively, .96, .94, and .87. A positive rating for reliability can

Table 2. Glossary of psychometric and statistical terminology.

Terminology	Definition
Construct validity	The extent to which a measurement corresponds to theoretical concepts (constructs) concerning the phenomenon under study[15].
Convergent validity	Convergent validity refers to the degree to which a measure is correlated with other measures that it is theoretically predicted to correlate with. In contrast, discriminant validity describes the degree to which the measure is not similar to (diverges from) other measures that it theoretically should not be similar to. Convergent validity and discriminant validity are variants of construct validity[15].
Correlation coefficient	An index that quantifies the linear relationship between a pair of variables (range -1 to 1) with the sign indicating the direction of the relationship and the numerical magnitude its strength. Values of -1 or 1 indicate that the sample values fall on a straight line, whereas a value of zero indicates the lack of any linear relationship between the two variables[16].
Criterion validity	The extent to which the measurement correlates with an external criterion of the phenomenon under study[15].
Cronbach's alpha	The estimate of the correlation between the total score across a series of items from a rating scale and the total score that would have been obtained had a comparable series of items been employed.[15] Cronbach's alpha is an index of internal consistency of a psychological test ranging from 0 to 1. (Guidelines for interpretation: < 0.60 unacceptable, 0.60-0.65 minimally acceptable, 0.70-0.80 respectable, 0.80-0.90 very good, and > 0.90 consider shortening the scale by reducing the number of items[17].)
Factor analysis	A set of statistical methods (e.g. maximum likelihood estimation), for analyzing the correlations among several variables in order to estimate the number of fundamental dimensions that underlie the observed data and to describe and measure those dimensions[15]. These underlying, unobservable, latent variables, are usually know as the common facors[17]. Using exploratory factor analysis, no hypothesis about the number and kind of common factors exists prior to analysis. In case of confirmatory factor analysis, the number of common factors has been predetermined.
Floor or ceiling effect	The number of respondents who achieved the lowest or highest possible score[10].
Goodness of fit	The degree of agreement between an empirically observed distribution and a mathematical or theoretical distribution[15].
Internal consistency	The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct[10].
Intraclass correlation	The proportion of variance of an observation due to between-subject variability in the 'true' scores of a measuring instrument[16].
Test retest reliability	An index of score consistency over a brief period of time (typically several weeks), usually the correlation coefficient determined between administration of the test twice with a certain amount of time between administrations[16].

only be given when the ICC is at least 0.70 in a sample size of at least 50 patients[10]. Because of missing values, the actual sample sizes used for ICC computation were 64 (MDADI), 35 (DHI) and, 49 (Dysphagia Severity Scale). Therefore, in case of the DHI, the reliability could not be determined appropriately, as a consequence of too few data. Both other two instruments are considered to have good test retest reliability.
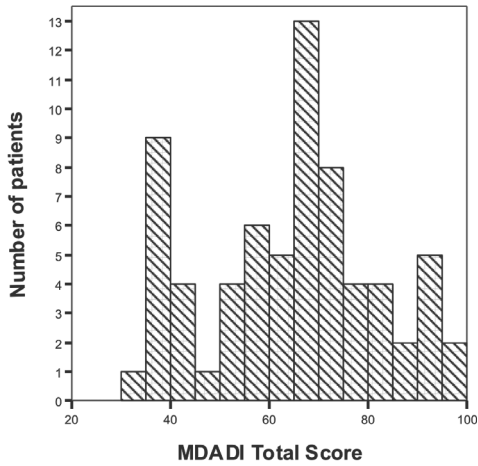
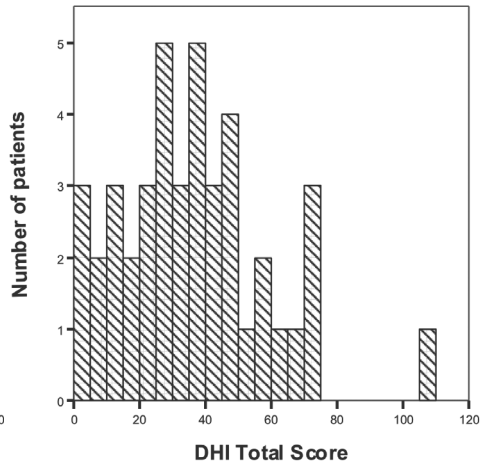**Figure 1A.** Data distribution on the MDADI

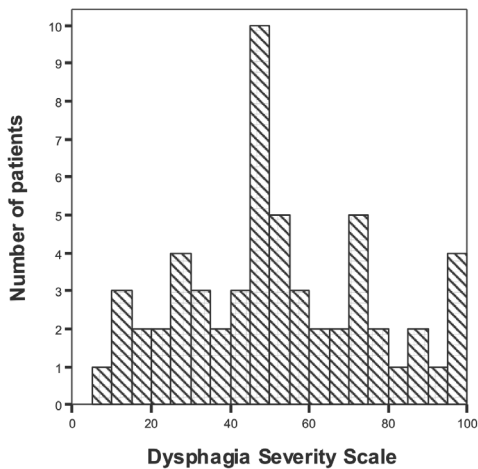**Figure 1B.** Data distribution on the DHI

Figure 1C. Data distribution on the Dysphagia Severity Scale

Internal consistency is an important measurement property for questionnaires and describes the extent to which items in a questionnaire (sub)scale are correlated, thus measuring the same concept. In case of an existing theoretical model or because the factor structure has been determined previously, confirmatory factor analysis should be applied in order to determine the number of (homogeneous) (sub)scales. Therefore, a confirmatory Maximum Likelihood (ML) factor analysis has been performed using all items of the MDADI to test whether three factors could be distinguished (namely, the three subscales). However, this three-factor model was rejected (goodness-of-fit test,

p<.000). A four-factor model referring to the global assessment as possible fourth factor, was rejected as well (p=.003). A confirmatory ML factor analysis using all items of the DHI and a three-factor model resulted too in rejection of the possibility of three underlying constructs or subscales (goodness-of-fit test, p<.000).

Still, as the subject population was rather limited, further analysis was performed to gather more information about the questionnaires' psychometric properties. Cronbach's alpha has been determined as it is considered an adequate measure of internal consistency reliability. Low Cronbach's alpha's suggest lack of correlation (α ≤ 0.70)[9], whereas high Cronbach's alpha's indicate redundancy of one or more items (α > 0.90)[9,11]. Cronbach's alpha's have been calculated for each (sub)scale separately of the MDADI and the DHI (see Table 3). All Cronbach's alpha's are between .76 and .94, thus indicating good internal consistency, although some redundancy may be present. Considering the outcome of the factor analyses without any obvious homogeneous (sub)scales detected as well as the adequate Cronbach's alpha's per (sub)scales, the internal consistency of both questionnaires might be described as yet unclear[10].

Table 3. Cronbach's alpha per (sub)scale of the MD Anderson Dysphagia Inventory (MDADI) and the Deglutition Handicap Index (DHI).

Quality of Life Scale		Cronbach's alpha
MDADI	Total Score	.94
	Global Assessment	n.a.
	Emotional Subscore	.86
	Functional Subscore	.82
	Physical Subscore	.87
DHI	Total Score	.93
	Emotional Subscore	.94
	Functional Subscore	.84
	Physical Subscore	.76

The associations among the four patient administered questionnaires plus the FOIS, and among the subscales per instrument were determined by nonparametric Spearman's correlation coefficients as well (Table 4 and 5). For the correlations coefficients (R), a minimum value for a strong correlation was set at 0.7 and above[12,13,14]. Correlation coefficients between 0.3 and 0.7 were considered to be a substantial correlation only and R-values < 0.3 were considered to be a weak correlation. Negative correlations are expected as all questionnaires but the DHI, associate lower scores

Table 4. Associations among the MDADI, the DHI, the Dysphagia Severity Scale, and the FOIS (nonparametric Spearman's correlation coefficients).

	MDADI					DHI				Dysphagia Severity Scale	FOIS[a]
	Total Score	Global Assessment	Emotional Subscore	Functional Subscore	Physical Subscore	Total Score	Emotional Subscore	Functional Subscore	Physical Subscore		
MDADI											
Total Score		.75** (74)	.94** (74)	.92** (74)	.91** (74)	-.87** (41)	-.89** (44)	-.70** (43)	-.57** (42)	.45** (57)	.53** (74)
Global Assessment			.68** (75)	.72** (75)	.66** (75)	-.72** (42)	-.65** (46)	-.64** (44)	-.65** (44)	.57** (57)	.44** (76)
Emotional Subscore				.81** (74)	.82** (74)	-.85** (41)	-.93** (45)	-.63** (43)	-.52** (43)	.43** (57)	.46** (75)
Functional Subscore					.77** (75)	-.82** (41)	-.86** (45)	-.65** (44)	-.54** (43)	.34** (57)	.53** (75)
Physical Subscore						-.82** (41)	-.75** (45)	-.78** (44)	-.62** (43)	.44** (57)	.45** (75)
DHI											
Total Score							.89** (42)	.84** (42)	.78** (42)	-.52** (30)	-.41** (42)
Emotional Subscore								.60** (44)	.54** (44)	-.43* (31)	-.13 (44)
Functional Subscore									.66** (42)	-.50** (31)	-.36* (44)
Physical Subscore										-.45** (32)	-.40** (46)
Dysphagia Severity Scale											.38** (57)
FOIS											

* Correlation is significant at the .01 level (2-tailed). ** Correlation is significant at the .05 level (2-tailed). [a] Lower scores indicate more severely impaired oral intake.

with more severely impaired quality of life or restricted functional oral intake. Correlations between the quality of life instruments and the functional feeding status proved rather low (-.013≤R≤.53). **Construct validity** could be determined by comparing (sub)scales from the MDADI and the DHI that were supposed to measure the same concept. Associations between similar subscales from both questionnaires as well as both total scores demonstrated whether or not they defined the same target construct (**convergent validity**). Correlation coefficients between both emotional, functional and physical subscales from the MDADI and the DHI were, respectively, -.93, -.65, and -.62. The correlations between the Dysphagia Severity Scale and both total scores from the MDADI and the DHI were rather low (respectively, .45 and -.52), whereas the correlation between both total scores of the MDADI and the DHI was strong (R=-.87). The mean correlation coefficients between the subscales of the MDADI and between the subscales of the DHI, were respectively, .80 (.66≤R≤.82) and .60 (.54≤R≤.66).

When considering the Swal-Qol as the reference standard or gold standard, the extent to which the MDADI and the DHI agreed or correlated with the Swal-Qol could be defined as the questionnaires' **criterion validity**. Table 5 presents the associations among the Swal-Qol versus the MDADI, the DHI, the Dysphagia Severity Index and the FOIS (nonparametric Spearman's correlation coefficients). The mean correlation coefficients between subscales from the Swal-Qol versus the total score of the MDADI, the total score of the DHI, and the Dysphagia Severity Scale were, respectively, .67 (.39≤R≤.86), -.61 (-.38≤R≤-.80), and .36 (.30≤R≤.73). Next, based on the authors' clinical experience, subscales that were considered to be of lesser importance to oropharyngeal dysphagia, were excluded by mutual consensus. Thus, when excluding the subscales Fear, Sleep, Fatigue, and Communication, the mean correlation coefficients were, respectively, .76 (.62≤R≤.86), -.71 (-.60≤R≤-.80), and .42 (.31≤R≤.73). According to Terwee et al. (2007), the correlation with the reference standard needs to be at least .70. Only after having excluded the less relevant subscales of the Swal-Qol, the MDADI as well as the DHI show satisfactory associations with the reference standard.

DISCUSSION & CONCLUSIONS

In this study the psychometric characteristics have been determined for the MDADI as well as the DHI. The Dysphagia Severity Scale was introduced to reveal any advantages or disadvantages of using elaborated questionnaires compared to a simple visual analogue scale, while the Swal-Qol was considered the refernce or gold standard. None of the quality of life questionnaires showed any floor of ceiling effects. The test retest reliability of the MDADI and the Dysphagia Severity Scale proved to be good. However,

Table 5. Associations among the Swal-Qol versus the MDADI, the DHI, the Dysphagia Severity Scale, and the FOIS (nonparametric Spearman's correlation coefficients).

Swal-Qol	MDADI					DHI				Dysphagia Severity Scale	FOIS[a]
	Total Score	Global Assessment	Emotional Subscore	Functional Subscore	Physical Subscore	Total Score	Emotional Subscore	Functional Subscore	Physical Subscore		
Burden	.84** (71)	.69** (73)	.79** (72)	.79** (72)	.78** (72)	-.68** (39)	-.77** (43)	-.54** (41)	-.46** (41)	.54** (55)	.50** (73)
Food Selection	.77** (69)	.67** (71)	.68** (70)	.80** (70)	.78** (70)	-.69** (38)	-.68** (42)	-.69** (40)	-.51** (40)	.42** (54)	.40** (71)
Eating Duration	.70** (69)	.57** (71)	.63** (70)	.66** (70)	.72** (70)	-.70** (39)	-.63** (43)	-.69** (41)	-.40* (41)	.38** (55)	.41** (71)
Eating Desire	.71** (70)	.56** (72)	.66** (71)	.68** (71)	.73** (71)	-.70** (39)	-.70** (43)	-.64** (41)	-.31* (41)	.32* (55)	.38** (72)
Fear	.57** (69)	.58** (71)	.52** (70)	.49** (70)	.59** (70)	-.38* (37)	-.42** (41)	-.32* (39)	-.30 (39)	.34* (53)	.31** (71)
Sleep	.39** (71)	.36** (73)	.31** (72)	.47** (72)	.42** (72)	-.47** (39)	-.47** (43)	-.40** (41)	-.35* (41)	.12 (55)	.26* (73)
Fatigue	.46** (71)	.43** (73)	.36** (72)	.46** (72)	.53** (72)	-.42** (39)	-.30* (43)	-.58** (41)	-.41** (41)	.25 (55)	.21 (73)
Communication	.63** (69)	.63** (71)	.52** (70)	.61** (70)	.61** (70)	-.48** (37)	-.46** (41)	-.36* (39)	-.47** (39)	.34* (53)	.42** (71)
Mental Health	.86** (69)	.72** (71)	.82** (70)	.83** (70)	.80** (70)	-.80** (37)	-.85** (41)	-.63** (39)	-.49** (39)	.42** (53)	.48** (71)
Social Functioning	.85** (71)	.73** (73)	.76** (72)	.90** (72)	.75** (72)	-.78** (39)	-.84** (43)	-.62** (41)	-.49** (41)	.43** (55)	.61** (73)
Symptoms	.62** (71)	.66** (73)	.53** (72)	.58** (72)	.61** (72)	-.60** (39)	-.54** (43)	-.51** (41)	-.73** (41)	.41** (55)	.33** (73)

* Correlation is significant at the .01 level (2-tailed). ** Correlation is significant at the .05 level (2-tailed). [a] Lower scores indicate more severely impaired oral intake.

because of too many missing data in case of the DHI, the test retest reliability of the DHI could not be determined even though the intraclass correlation coefficients were rather high. The internal consistency using Cronbach's alpha's seemed to be good. However, when applying confirmatory factor analysis, the underlying constructs as defined by the subscales per questionnaire could not be distinguished. Probably, because of unclear constructs, only both emotional subscales were strongly correlated, whereas the associations between the other corresponding subscales were just moderate. Overall, the Dysphagia Severity Scale, showed rather low correlations with the other three questionnaires. It seemed that a detailed questionnaire could not be replaced by a single one item scale, quantifying the severity of the swallowing disorder. The concepts being measured proved to be different. When considering the criterion validity, the MDADI as well as the DHI showed satisfactory associations with the Swal-Qol after having removed its less relevant subscales.

In conclusion, when considering the validity and reliability of the Dutch version of the MDADI and the DHI, not all psychometric characteristics have been met sufficiently. In general, the importance of determining these psychometric characteristics and of objectifying concepts such as validity and reliability, must be stressed when developing a questionnaire. If a questionnaire's characteristics prove to be poor, the study results cannot be interpreted correctly nor can any clinical relevance be determined. Therefore, it is recommended that in future outcome studies, only quality of life questionnaires will be used that show sufficiently good psychometric characteristics.

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