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Validation of the Finnish MD Anderson Dysphagia Inventory (MDADI) in patients with head and neck cancer

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The aim of this study was to translate and adapt the MD Anderson Dysphagia Inventory (MDADI) questionnaire into Finnish and validate it in patients with head and neck cancer (HNC). A total of 94 participants were included: 64 dysphagic HNC patients and 30 non-dysphagic age- and gender-matched controls. The MDADI was formally translated using the forward-backward method and feasibility, test-retest reliability, internal consistency, score distribution, known-group validity, and patient feedback and were analyzed. Criterion and convergent validities were tested against the previously validated dysphagia questionnaire F-EAT-10. The results showed good variability and no floor or ceiling effects in the dysphagic group (age range 31 to 85 years, mean 67.8, SD 11.2). In all MDADI subscales, the internal consistency reliability was high (Cronbach's alpha > 0.8). Moreover, the intraclass correlation in test-retest ($n = 55$) was high (> 0.9) in all subscales. The MDADI was able to discriminate between dysphagic and non-dysphagic participants: the mean total score was 73.6 for the dysphagic group and 99.9 for the control group ($p > 0.001$). The correlations between the MDADI and the F-EAT-10 were strong demonstrating criterion and convergent validities. Patient feedback of the MDADI was positive. In conclusion, the Finnish MDADI is a valid instrument to assess dysphagia-related quality of life in patients with HNC, offering enhanced clinical and research utility.

Keywords Dysphagia, Swallowing, Health-related quality of life, Psychometric validation

Head and neck cancer (HNC) is the seventh most common malignancy worldwide, accounting for more than 900,000 cases annually[1]. At diagnosis, up to 28% of all HNC patients report swallowing difficulties (dysphagia)[2]. Moreover, dysphagia is a common side effect of HNC treatments, thus ultimately affecting up to 45% of HNC survivors[3]. It is also shown to highly correlate with worse overall quality of life in oropharyngeal cancer patients[4].

At present, there are no disease-specific validated Finnish swallowing questionnaires developed for HNC patients. To date, the only validated Finnish swallowing questionnaire is the Finnish version of the Eating Assessment Tool (F-EAT-10)[5]. The F-EAT-10 is a generic 10-item tool validated in patients with dysphagia of various etiology: in the validation study, the most common causes for dysphagia were functional (26.5%), neurological (12.8%), esophageal (12.0%), and age-related dysphagia (10.3%). Furthermore, the etiology of dysphagia was HNC or esophageal cancer in 13.7% of the patients. The sensitivity of the F-EAT-10 may be insufficient for HNC patients because of the small number of questions[6].

In HNC patients, MD Anderson Dysphagia Inventory (MDADI) has shown high internal consistency and reliability[7]. It has been successfully validated in various cultures and languages in Europe[8–13], Asia[14–19], and Latin America[20]. A preliminary Finnish translation of MDADI has already been used in published research, although it is yet to be validated[21–23].

This study aimed to translate, adapt, and validate the Finnish version of the MDADI in HNC patients with dysphagia, and contrast it to an age- and gender-matched control group without dysphagia. Following validation guidelines, we aimed to evaluate its psychometric properties by analyzing the internal consistency, the test-retest reliability, the feasibility, the construct validity, and ceiling and floor effects[24].

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Materials and methods

Patients

A list of survivors with head and neck cancer diagnosed between January 2010 and December 2021 who had received radiation therapy in Turku University Hospital was collected from Auria Clinical Informatics ($n = 146$). According to the evaluation of the clinician recorded in the patient charts, 138 of these patients had permanent symptoms of dysphagia. These patients were recruited by phone. Patients who reported significant dysphagia that affects their daily life in the phone interview and who gave written informed consent to participate were included in the study.

In addition, we recruited a sample of age- and gender-matched non-dysphagic controls ($n = 30$) from the local community. The control group included nonhospitalized participants who also gave written informed consent. For non-dysphagic controls, the inclusion criteria were specified as follows: Finnish as native language, no previous HNC, no self-reported dysphagia, and no previous head and neck radiation therapy.

A mail-out/mail-back procedure was used: the MDADI and the F-EAT-10 questionnaires were mailed to all participants. Moreover, the dysphagic participants were asked to give written feedback about the MDADI questionnaire: whether the questions were easy to understand, and other comments. Furthermore, all dysphagic participants were asked to complete the MDADI questionnaire again on a second occasion one week after the time of enrollment. Patients who did not return the questionnaires were not reminded.

The study plan was reviewed by the Regional Ethics Committee (26/1801/2022) at Turku University Hospital. The Ethics Committee decided that since this study does not involve an intervention, the Medical Research Act (Finlex No. 488/1999) does not apply to this study. Hence, no ethical approval was required, and that the study could be performed without further ethical review. The research was performed in accordance with the Declaration of Helsinki.

Patient-Reported outcome measures

The MDADI

The MD Anderson Dysphagia Inventory (MDADI) was developed in the United States in 2001. It is a self-administered questionnaire designed specifically for evaluating the impact of dysphagia on the health-related quality of life (HRQoL) of patients with head and neck cancer. The questionnaire consists of six subscales: global (one question), emotional (6 questions), functional (5 questions), physical (8 questions), composite (19 questions), and total (all 20 questions). The global assessment question demonstrates how swallowing limits the patient's overall QoL. The other subscales have multiple questions relating to the same domain. The emotional subscale consists of affective responses to dysphagia. The functional subscale represents the impact of dysphagia on daily activities. The physical subscale demonstrates self-perceptions of dysphagia. In an individual's within-subject MDADI scores, a change of 20 points is interpreted meaningful[25], whereas between groups of HNC patients, a 10-point difference in composite MDADI scores is associated with clinically meaningful between-group differences in swallowing function[26].

In the original English MDADI, two of the items (E7 and F2) included a negation, and thus were scored as 5 points for strongly agree and 1 point for strongly disagree. All other items were scored as 1 point for strongly agree and 5 points for strongly disagree. Therefore, a higher MDADI score indicated better QoL. However, in the validation process of the Swedish MDADI, a systematic error was noted in the two reversed items (E7 and F2)[27]. Several participants systematically misinterpreted the negation and answered in the same way as to all other items. This systematic error was confirmed by interviews. Therefore, the Swedish version of MDADI was revised so that all items are scored as 1 point for strongly agree and 5 points for strongly disagree[28]. We decided to follow the Swedish example to avoid this systematic error.

The F-EAT-10

The Finnish version of the Eating Assessment Tool (F-EAT-10) is the only previously validated dysphagia questionnaire for Finnish speakers. In Europe, it has also been validated in Spain[29], Italy[30], Portugal[31], Sweden[27], Türkiye[32], Greece[33], the Netherlands[34], and France[35]. The original EAT-10 was developed in the United States in 2008 to provide a rapid dysphagia instrument. It consists of ten items related to main aspects of dysphagia. All items are scored from no difficulty (0 points) to severe difficulty (4 points). A sum score of > 2 points is regarded suggestive of dysphagia. The MDADI was referenced against the F-EAT-10 to establish criterion validity. We hypothesized that MDADI scores correlate well with F-EAT-10 scores, as both questionnaires measure the same concept of swallowing-related QoL. Written consent to include the F-EAT-10 in this article was requested from Janet Skates, Nestlé Health Science Consultant.

Translation of the MDADI into Finnish

We translated the MDADI using the formal forward-backward method according to Wild et al.[36] Initially, our group of native Finnish-speaking medical professionals developed two independent forward translations of the MDADI questionnaire from English to Finnish. Of these preliminary translations, our group developed a single forward translation. Thereafter, a back translation was performed by a native English-speaking professional translator. Finally, two independent otolaryngologists, an independent speech therapist, and an independent nutritionist evaluated the original and the back-translation. In comparison of these questionnaires, the main difference was the removal of the negation in the items E7 and F2, as explained above. No critical differences were found.

Statistics

IBM SPSS Statistics version 29 was used in the statistical analyses. For testing between two groups, the Mann-Whitney test was used, and for testing between >2 groups, the Kruskal–Wallis test was used. $p < 0.05$ was considered statistically significant. Correlations were tested with Spearman's correlation coefficient (r), where a correlation coefficient <0.3 was considered a weak correlation, 0.3–0.7 moderate correlation, and >0.7 a strong correlation[37]. Internal consistency reliability was tested with Cronbach's α coefficient. Test-retest reliability was analyzed with intraclass correlation (ICC) by longitudinally comparing the questionnaire at the time of enrollment and 7 days after. Known-group validity was calculated between the dysphagic group and the non-dysphagic control group. Floor and ceiling effects were considered present if more than 15% of respondents achieved the extreme summary score[38]. Our hypothesis was that the non-dysphagic control group would include the most highly functioning participants and represent the highest possible score (ceiling).

Results

Recruitment of participants

Of the 65 eligible HNC patients, 64 returned written consent to participate (Fig. 1). The response rate was 98.5%. Thus, a total of 94 participants were included in this study: 64 patients with HNC in the dysphagic study group, and 30 age- and gender-matched non-dysphagic controls. The clinical characteristics of all the participants are presented in Tables 1 and 2.

Feasibility

All participants had completely finished the questionnaires they returned. There were no missing values. Therefore, the survey had 100% feasibility within the studied population.

Test-Retest reliability

All participants with HNC were asked to fill in a second administration of the MDADI, mailed seven days after the first administration. It was returned by 55 (85.9%) of the participants. The test-retest reliability was good[39] for each subscale (intraclass correlation coefficient ICC >0.80), Table 3.

Internal consistency

For each subscale, the internal consistency was high regarding the Cronbach's alpha coefficients (> 0.80) in the dysphagic group, Table 3. The global subscale consists of only one item, and thus its Cronbach's alpha coefficient could not be calculated.

Features of score distribution

In all subscales, the full range (20 to 100) of the score distribution was observed in the dysphagic HNC group (Table 4). However, in the non-dysphagic control group, the ranges were small with ceiling effects in all subscales, as expected, Table 4.

Criterion and convergent validities

Criterion and convergent validities were assessed in the dysphagic group by correlations between the MDADI and the previously validated F-EAT-10, Table 5. We hypothesized high negative correlations between the MDADI total and composite subscales and the F-EAT-10 total score (higher QoL with lower symptom burden).

As expected, a strong negative correlation (Spearman's correlation coefficient $r<-0.70$) was found between F-EAT-10 total score and the MDADI total, composite, emotional, functional, and physical subscales. Moreover, a strong negative correlation was found between the F-EAT-10 RP (reduced pleasure of eating) and the MDADI total, composite, emotional, functional, and physical subscales. Furthermore, the F-EAT-10 SSD (swallowing solids disorder) had strong negative correlation with the MDADI total, composite, emotional, and physical subscales. A single weak correlation was found between the F-EAT-10 CD (cough during eating) and the MDADI global subscale ($r=-0.213$). All other correlations between the MDADI and the F-EAT-10 were moderate ($r=-0.7–(-0.3)$).

Known-Group validity

The MDADI was able to distinguish between dysphagic HNC patients and non-dysphagic control group, Table 6. There was a statistically significant difference ($p < 0.001$) between the dysphagic and the non-dysphagic group in all subscales: total, composite, global, emotional, functional, and physical. The mean composite score was 74.3 for the dysphagic group and 99.9 for the non-dysphagic control group ($p < 0.001$).

Patient feedback

All 64 HNC patients were asked to give written feedback about the MDADI. Most of the patients did not submit feedback. Seven patients wrote that the questions were easy to understand. One patient stated that the F-EAT-10 was easier and quicker to fill in than the MDADI.

Discussion

To optimize the treatment of HNC patients, understanding swallowing-related QoL is essential. However, no Finnish dysphagia-specific questionnaires designed for HNC patients have yet been validated. This study translated and cross-culturally adapted the original English MDADI into a Finnish version, and evaluated its validity and reliability among dysphagic patients with HNC compared to an age- and gender-matched non-dysphagic control group.

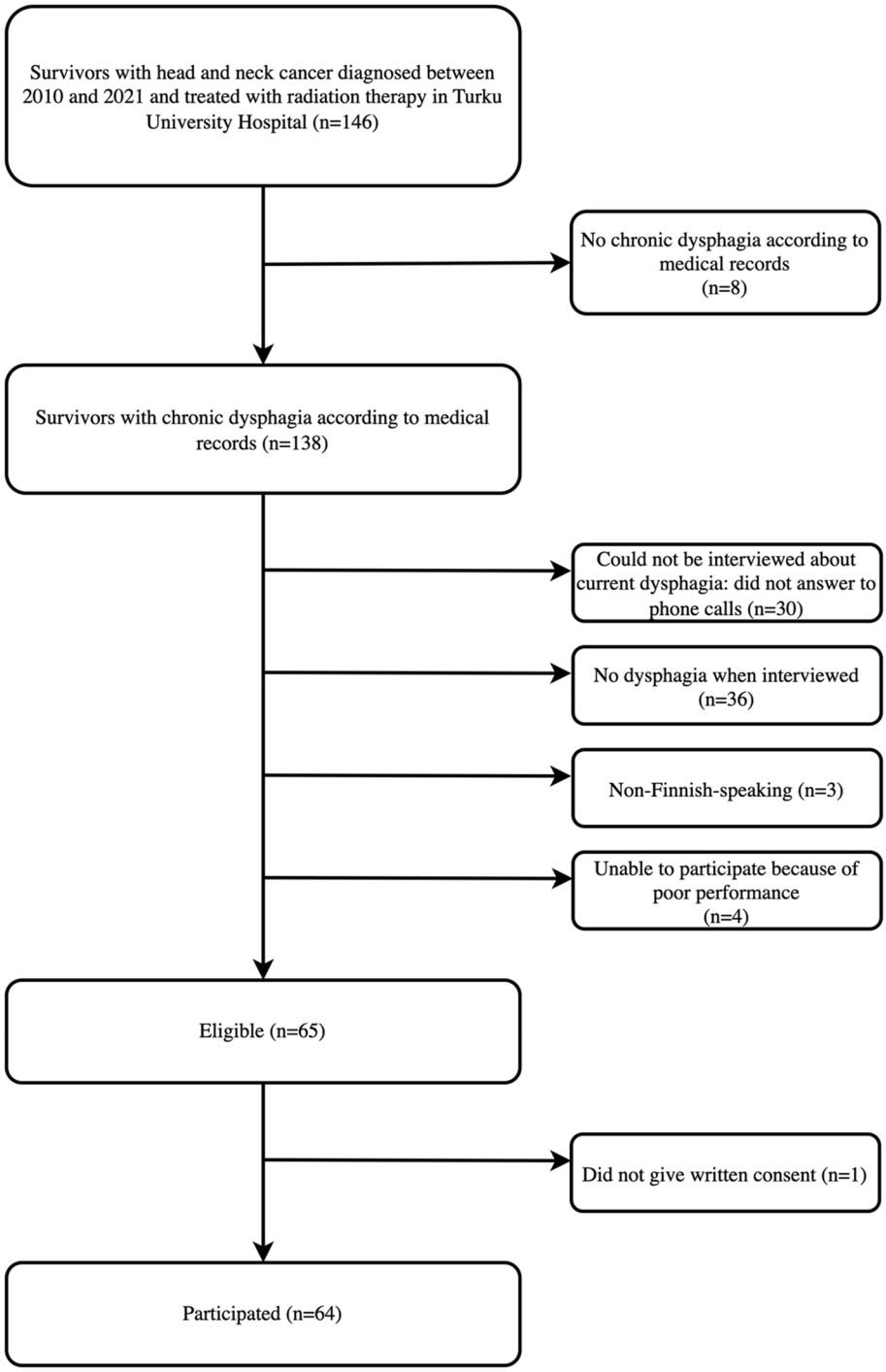

Fig. 1. Flow chart of recruitment of dysphagic patients with head and neck cancer. Flow chart made with draw.io tool (Draw.io).

The Finnish MDADI showed good psychometric properties. It was also able to discriminate between dysphagic and non-dysphagic participants with statistically significant differences in all subscales ($p < 0.001$). The composite score between-group difference between the dysphagic and the non-dysphagic group was 25.6 points, which means it is also interpreted as clinically meaningful (≥ 10 points)[26].

Although all dysphagic participants were asked to give feedback about the MDADI, only eight (12.5%) participants provided written feedback. Seven of the responses were positive, stating all MDADI items were easy to understand. One participant remarked that the F-EAT-10 was easy and quick compared to the MDADI. The MDADI includes double the amount of questions compared to the F-EAT-10, and therefore also gives more elaborate information about dysphagia-related QoL. In routine clinical practice outside of research settings,

	Dysphagic study group ($n = 64$)	%	Control group ($n = 30$)	%
Age (years)				
< 45	2	3.1	1	3.3
45–54	9	14.1	4	13.3
55–64	4	6.3	2	6.7
65–74	31	48.4	15	50.0
75–84	17	26.6	8	26.7
> 85	1	1.6	0	0.0
Gender				
Female	21	32.8	11	36.7
Male	43	67.2	19	63.3
Education	Missing information 9			
Elementary school	12	18.8	4	13.3
High school or vocational education	31	48.4	8	26.7
University or higher	12	18.8	18	60.0
Marital status				
Cohabitation with a partner	45	70.3	26	86.7
Cohabitation with a person other than a partner	1	1.6	0	0.0
Living alone	18	28.1	2	6.7
Alcohol consumption				
Current heavy	1	1.6	0	0.0
Previous heavy	14	21.9	0	0.0
No history of heavy consumption	49	76.6	3	10.0
Smoking				
Yes	15	23.4	1	3.3
Recent quitter (< 6 months ago)	0	0.0	0	0.0
Early quitter (> 6 months ago)	28	43.8	5	16.7
Never smoker	21	32.8	24	80.0
Pack-years	Mean 30.9 (SD 19.8), median 30.0 (IQR 26.0)		Mean 12 (SD 10.4), median 10 (IQR 15)	
One or more coexisting disease/s	50	78.1	21	70.0
Regular medication				
0 medicines	18	28.1	6	20.0
1–2 medicines	11	17.2	15	50.0
3–4 medicines	10	15.6	6	20.0
> 5 medicines	25	39.1	3	10.0

Table 1. Participant characteristics. SD = standard deviation. IQR = interquartile range.

a shorter questionnaire may be more appropriate than the MDADI. In a recent study, it appeared feasible to abbreviate the 20-item MDADI questionnaire to a 5-item "MiniDADI" questionnaire[40].

This study has several limitations. We did not perform structured interviews about the comprehensibility of the MDADI; however, we collected written feedback. Moreover, we had no data about the diet of the participants. However, the MDADI aims to measure subjective QoL, and thus the diet may not be important to include in analyses. In this article, we lack analysis of the responsiveness of the instrument[41], but in a Swedish longitudinal study, the MDADI was found to be sensitive to change and to show convergent results against other established instruments[28].

The strengths in our study were the inclusion of an age- and gender-matched control group, good balance with education and marital status, good gender and age balance, and a longitudinal test-retest measurement returned by many patients. In addition, our study population represented many HNC subsites. The clinical characteristics and comorbidities were well known in both the dysphagic and the non-dysphagic study groups. Furthermore, we collected and received good patient feedback about the clarity of the Finnish MDADI.

Valid QoL instruments are essential in evaluation of outcomes of new treatments. Moreover, most HNC patients find QoL questionnaires (QLQs) useful to communicate their health concerns to their clinician[42]. QoL instruments may even be able to predict future QoL and survival[43].

Conclusions

The Finnish version of the MDADI showed good validity and reliability. Moreover, it was able to differentiate between dysphagic and non-dysphagic patients. Furthermore, it could assess the severity of the impact of dysphagia on QoL and social functioning. Therefore, it can be used clinically to measure the swallowing-related QoL among HNC patients in Finland and to compare the outcomes of different treatment modalities for HNC.

		%
Age	Mean 67.8 (SD 11.2)	
	Median 70.5 (IQR 11)	
	Minimum 31, maximum 85	
Time from diagnosis to study entry (years)	Mean 4.6 (SD 1.6)	
	Median 4.5 (IQR 2)	
	Minimum 1, maximum 7	
Dryness of mouth	41	64.1
Feeding		
Oral	58	90.6
Partly oral, partly percutaneus endoscopig gastrostomy (PEG)	5	7.8
PEG only	1	1.6
PEG installed during cancer treatment	42	65.6
Weight loss since diagnosis, current situation (kg)	Median 6 (IQR 10)	
	Mean 7.3 (SD 6.0)	
	Minimum 0, maximum 34	
Treatment modality		
Surgery only	0	0.0
Radiation therapy only	2	3.1
Chemoradiation	34	53.1
Surgery and radiation therapy	2	3.1
Surgery and chemoradiation	26	40.6
Cancer subsite		
Oral cavity	13	20.3
Oropharynx	33	51.6
Larynx	7	10.9
Hypopharynx	5	7.8
Parotid	1	1.6
Nasopharynx	3	4.7
Unknown primary	1	1.6
Sinonasal	1	1.6
T stage of tumor	Information missing 1 (unknown primary)	
T0-T1	10	15.6
T2	28	43.8
T3	4	6.3
T4, T4a, or T4b	21	32.8
N		
N0	26	40.6
N1	12	18.8
N2, N2a, N2b, or N2c	36	56.3
N3	2	3.1
M		
M0	60	93.8
M1	4	6.3
p16		
Negative	25	39.1
Positive	25	39.1
Information missing	14	21.9
Cancer stage		
Stage I	10	15.6
Stage II	19	29.7
Stage III	10	15.6
Stage IV+	25	39.1

Table 2. Dysphagic group with head and neck cancer ($n = 64$), clinical characteristics. SD = standard deviation. IQR = interquartile range.

Subscales	Items	Internal consistency, Cronbach's alpha	Test-retest ICC (95% CI), $n = 55$
Global	1	not applicable	0.972 (0.952–0.984)
Emotional	6	0.864	0.965 (0.941–0.980)
Functional	5	0.819	0.964 (0.931–0.981)
Physical	8	0.85	0.973 (0.954–0.984)
Composite (all questions but global)	19	0.941	0.983 (0.970–0.990)
Total (all questions)	20	0.944	0.984 (0.972–0.990)

Table 3. The internal consistency reliability and the test-retest reliability of the MDADI subscales in dysphagic patients with head and neck cancer, $n = 64$. ICC = intraclass correlation. CI = confidence interval.

	Subscales	Items	Range	Mean	Median	SD	%Floor	%Ceiling
Dysphagic group with head and neck cancer, $n = 64$	Total	20	20–99	73.6	78	18.2	1.6	0
	Composite	19	20–100	74.3	78.4	18.3	1.6	3.1
	Global	1	20–80	60.9	70	22.1	12.5	0
	Emotional	6	20–100	72.9	76.7	20.5	1.6	12.5
	Functional	5	20–100	80.2	84	19	1.6	14.1
	Physical	8	20–100	71.7	72.5	18.8	1.6	3.1
Non-dysphagic control group, $n = 30$	Total	20	98–100	99.9	99.9	0.4	0	90
	Composite	19	97.9–100	99.9	100	0.5	0	90
	Global	1	100–100	100	100	0	0	100
	Emotional	6	100–100	100	100	0	0	100
	Functional	5	100–100	100	100	0	0	100
	Physical	8	95–100	99.7	100	1.1	0	90

Table 4. Score distributions of the MDADI. SD = standard deviation.

	F-EAT-10										
MDADI	WL	AM	SLD	SSD	SPD	PS	RP	FS	CD	SS	Total score
Global	-0.376	-0.319	-0.426	-0.613	-0.552	-0.447	-0.636	-0.434	-0.213	-0.492	-0.641
p	***0.002***	***0.01***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	*0.092*	***<0.001***	***<0.001***
Total	-0.499	-0.641	-0.572	-0.757	-0.64	-0.445	-0.823	-0.478	-0.367	-0.525	-0.831
p	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***0.003***	***<0.001***	***<0.001***
Composite	-0.502	-0.648	-0.576	-0.753	-0.626	-0.438	-0.821	-0.47	-0.365	-0.516	-0.824
p	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***0.003***	***<0.001***	***<0.001***
Emotional	-0.434	-0.682	-0.54	-0.702	-0.581	-0.395	-0.79	-0.465	-0.373	-0.516	-0.799
p	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***0.001***	***<0.001***	***<0.001***	***0.002***	***<0.001***	***<0.001***
Functional	-0.427	-0.691	-0.505	-0.685	-0.636	-0.317	-0.706	-0.409	-0.397	-0.45	-0.762
p	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***0.011***	***<0.001***	***<0.001***	***0.001***	***<0.001***	***<0.001***
Physical	-0.513	-0.499	-0.531	-0.708	-0.612	-0.445	-0.795	-0.485	-0.324	-0.481	-0.773
p	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***<0.001***	***0.009***	***<0.001***	***<0.001***

Table 5. Criterion and convergent validities. Scale-scale correlations (Spearman's correlation coefficient r) for MDADI and F-EAT-10 in dysphagic patients with head and neck cancer, n=64.
MDADI=MD Anderson Dysphagia Inventory. F-EAT-10=Finnish version of the Eating Assessment Tool. WL=weight loss, AM=ability to go out for meals, SLD=swallowing liquids disorder, SSD=swallowing solids disorder, SPD=swallowing pills disorder, PS=painful swallowing, RP=reduced pleasure of eating, FS=food sticks in the throat, CD=cough during eating, SS=stressful swallowing.

MDADI subscales	Dysphagic group with head and neck cancer $n = 64$		Non-dysphagic control group $n = 30$		
	Mean	SD	Mean	SD	p
Total	73.6	18.2	99.9	0.4	< 0.001
Composite	74.3	18.3	99.9	0.5	< 0.001
Global	60.9	22.1	100	0	< 0.001
Emotional	72.9	20.5	100	0	< 0.001
Functional	80.2	19	100	0	< 0.001
Physical	71.7	18.8	99.7	1.1	< 0.001

Table 6. Known-group validity: differences between dysphagic and non-dysphagic participants. SD = standard deviation.

Data availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Author contributions

All authors (PR, IK, and HI) planned the study together. PR recruited the participants. PR conducted the statistical analyses. All authors participated in the writing process of the manuscript. PR prepared the tables and the figures. All authors reviewed the manuscript.

Declarations

Competing interests

The authors declare no competing interests.

Additional information

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