

RESEARCH REPORT

# Assessment of patients with head and neck cancer using the MD Anderson Dysphagia Inventory: Results of a study into its comprehensiveness, comprehensibility and relevance to clinical practice

Kate Toft<sup>1,2</sup> | Catherine Best<sup>1</sup> | Jayne Donaldson<sup>1</sup>

<sup>1</sup>University of Stirling, Stirling, UK

<sup>2</sup>NHS Lothian; Western General Hospital, Edinburgh, UK

## Correspondence

Kate Toft, Department of Speech & Language Therapy, Western General Hospital, Crewe Road South, Edinburgh, EH4 2XU.  
Email: [kate.toft@nhslothian.scot.nhs.uk](mailto:kate.toft@nhslothian.scot.nhs.uk)

## Abstract

**Background:** The MD Anderson Dysphagia Inventory (MDADI) is a widely used patient-reported outcome measure (PROM) which assesses dysphagia-related quality of life (QoL) in head and neck cancer (HNC). Despite its common use in HNC research and clinical practice, few of its psychometric properties have been reappraised since its inception. The aim of this study was to perform a survey-based qualitative analysis of UK HNC clinicians' perceptions of the content validity of the MDADI, evaluating it across the parameters of relevance, comprehensiveness and comprehensibility as per the COSMIN guideline for PROM assessment.

**Results:** Four themes relating to the content validity of the MDADI were identified: (1) MDADI items lack clarity of definition of the terms 'swallowing', 'eating' and 'dysphagia'; (2) the MDADI is perceived to be overly negative in tone including items that service users may find distressing or disempowering; (3) items in the tool are exclusory to specific subgroups of patients, such as those who are nil by mouth or socially isolated; and (4) modifications to the MDADI were suggested and encouraged to make it more clinically useful and patient-centred.

**Conclusions:** This study indicates that MDADI's content validity is 'insufficient' when rated by COSMIN parameters. This has significant implications for its continued use in HNC research and clinical practice. Further re-evaluation of the content validity of the MDADI is warranted, with potential future amendment of items being indicated if the results of this study are corroborated in subsequent research.

## KEYWORDS

content validity, dysphagia, head and neck cancer, patient reported outcome measures, qualitative research

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2024 The Authors. *International Journal of Language & Communication Disorders* published by John Wiley & Sons Ltd behalf of Royal College of Speech and Language Therapists.



### What this paper adds

#### *What is already known on the subject*

- The MD Anderson Dysphagia Inventory (MDADI) patient-reported outcome measure of dysphagia-related quality of life is widely used in clinical practice and international clinical trials. Content validity is considered to be the most important property of a tool when assessing its psychometric strengths and weaknesses; however, the MDADI's content validity has not been reappraised since its initial development.

#### *What this paper adds to existing knowledge*

- This study presents UK speech and language therapists' opinions and experience of the content validity of the MDADI and this first reappraisal of its content validity since its initial development highlights several issues with this psychometric parameter of the tool. This study highlights that further re-evaluation of the content validity of the MDADI is warranted, with potential future amendment of items being indicated if the results of this study are corroborated in subsequent research.

#### *What are the potential or actual clinical implications of this work?*

- Clinicians cannot assume that commonly used outcomes tools have strong psychometric profiles. Consideration of the content validity of outcomes tools during selection for use in clinical and research practice should be key, as this will encourage use of tools that produce relevant, valid data that can contribute meaningfully to patient-centred care.

## INTRODUCTION

Difficulties with eating, drinking and swallowing are commonly reported by patients as one of the most impactful outcomes of their head and neck cancer (HNC) and its treatment (Mendez et al., 2020), and people with HNC-related dysphagia describe a complex interaction between it and other social, emotional and physical aspects of their lives (Dawson et al., 2019). Recent international guidance on HNC practice emphasises the importance of assessing, monitoring and managing the psychosocial impact of dysphagia (Baijens et al., 2021; Verdonck-de Leeuw et al., 2022). The impact of dysphagia on peoples' lives can be measured by assessing dysphagia-related quality of life (QoL), which is the patient's perception of the impact of swallowing difficulties across social, functional and psychological domains (Speyer et al., 2014).

The only tool designed specifically for assessing dysphagia-related QoL specifically in people with HNC is the MD Anderson Dysphagia Inventory (MDADI) (Chen et al., 2001).

The MDADI is one of the most frequently used dysphagia outcome assessment tools in HNC research practice internationally (Ojo et al., 2012) and is often used as a main outcome tool in multicentre trials (Castellano & Sharma, 2019; Hutcheson et al., 2016; Martino et al., 2021; Mehanna et al., 2017; Nichols et al., 2020; Owadally et al., 2015; Petkar et al., 2016; Thomson et al., 2023). The MDADI is also often used as a 'gold standard' in the validation of other dysphagia assessment tools for use with people with HNC (Dwivedi et al., 2010; Hutcheson et al., 2017).

The MDADI is a self-administered patient-reported outcome measure (PROM) which quantifies swallowing related QoL. It was originally validated on a cross-sectional sample of 100 English-speaking adult patients with HNC and dysphagia in the United States in the 1990s (Chen et al., 2001). The tool consists of 20 items rated on a 5-point Likert scale. Scoring the tool produces a global score (MDADI—G), scored from the first item ('my swallowing impacts my day-to-day life'), and a composite score (MDADI—C) of the remaining 19 items. MDADI-G and MDADI-C scores range from 20 (low QoL) to 100 (high QoL).



The ‘content validity’ of a PROM refers to whether it covers all of the important and relevant aspects of the subject under investigation (Connell, 2018), and can be established by asking patients and clinicians about the comprehensiveness, relevance and comprehensibility of the items in the tool (Terwee et al., 2018). Content validity is the degree to which the content of an instrument is an adequate reflection of the construct to be measured (Verdonck-de Leeuw et al., 2022). The COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments) initiative (Terwee et al., 2018) identifies three core aspects of content validity: (1) relevance (all items in a PROM should be relevant for the construct of interest within a specific population and context of use), (2) comprehensiveness (no key aspects of the construct should be missing) and (3) comprehensibility (the items should be understood by patients as intended). Content validity is the most important measurement property of a PROM and the most challenging to assess (Terwee et al., 2018). Content validity of existing PROMs should be assessed in a content validity study by systematically asking patients and professionals (e.g., clinicians, researchers) about the relevance, comprehensiveness and comprehensibility of the items.

Since the MDADI’s inception more than 20 years ago, studies have appraised its psychometric properties based on the original validation paper (Hutcheson et al., 2016; Khan et al., 2015; Lin et al., 2022; Ojo et al., 2012; Patel et al., 2017; Pedersen et al., 2016; Timmerman et al., 2014; Zraick et al., 2012); however, surprisingly few aspects of the MDADI have been re-evaluated through original research given the tool’s widespread use within HNC practice. To date the concurrent validity (Khan et al., 2015; Pedersen et al., 2016), interpretability (Hutcheson et al., 2016), construct validity (Lin et al., 2022), minimal clinically important differences (MCID; Hutcheson et al., 2016), readability (Zraick et al., 2012) and potential item redundancy (Lin et al., 2022) of the MDADI have been explored; however, no research exists further examining the content validity of the tool.

Concurrent validity with other swallow assessment tools has thus far shown to be moderate for the Water Swallow Test (WST) and the Penetration-Aspiration Scale (PAS; Pedersen et al., 2016), and strong at the 12-month post-treatment point only for the Performance Status Scale—Head & Neck: Normalcy of Diet (Khan et al., 2015). This amounts to weak evidence for a strong correlation between the MDADI and diet texture restriction, but only a weak or moderate correlation with clinical measures of swallowing (PAS and WST). Studies to date considering the concurrent validity of the MDADI are compromised by heterogeneous datapoints and small sample sizes.

Hutcheson, Barrow (Hutcheson et al., 2016) focus on defining what a ‘clinically relevant difference’ (MCID) in

composite MDADI scores constitutes with a retrospective cross-sectional study of 1136 HNC patients. MDADI scores were compared with ‘clinical anchors’ of feeding tube status, diet level and aspiration status as determined by Modified Barium Swallow instrumental assessment. Statistical analysis showed that an average difference of 10 points in MDADI-C scores differentiated between patients who were or were not feeding tube dependent and aspirators, and between distinct diet levels as measured on the Performance Status Scale for Head and Neck Cancer diet scale. Although data from a statistically powerful number of patients were analysed, the analysis did not consider longitudinal within-patient score changes and therefore what constitutes a meaningful difference in MDADI-C scores for individual patients. In addition, the results of this study have not been triangulated with qualitative data from clinicians or patients to confirm its clinical relevance.

Lin et al. (Lin et al., 2022) explore whether a multivariate factor analysis could reduce item redundancy thereby generating a shortened version of the 20-item MDADI tool. The authors present preliminary findings that the tool could be reduced to a 5-item ‘MiniDADI’ whilst emphasizing that further validation of the MiniDADI would be required prior to its adoption in clinical practice, due to the geographically limited nature of their patient data and incomplete missing data analysis, and that the test-retest reliability and concurrent validity of the tool have yet to be assessed.

Zraick et al. (Zraick et al., 2012) assess the readability of the MDADI and relate this to average reading levels of English-speaking adults living in the United States. The authors found the readability of the MDADI equates to ‘college level’, that is, a high level of literacy. This means that there is potential for the MDADI to be too linguistically complex for patients with lower literacy levels, thereby affecting these patients’ ability to complete the tool and the validity and reliability of the data it generates. This has relevance given that evidence exists in the literature that HNC patients have complex health literacy needs (Beitler et al., 2010; Jabbour et al., 2017).

Three papers present a more comprehensive analysis of the psychometric properties of the MDADI: Ojo et al. (Ojo et al., 2012), Patel et al. (Patel et al., 2017) and Timmerman et al. (Timmerman et al., 2014). However, these papers do not focus solely on the MDADI tool, but rather include an analysis of it alongside other dysphagia outcome measures.

These three reviews all assess slightly different profiles of MDADI properties, and their assessments of the MDADI do not agree in some domains. For example, in the domain of content validity, not only does each paper define this parameter slightly differently, but all three



papers rate the criterion differently despite all making their assessment based on the same single MDADI origin paper. Ojo et al. (Ojo et al., 2012) do not report details of content validity, Timmerman et al. (Timmerman et al., 2014) report analysis results as 'indeterminate' whereas Patel et al. (Patel et al., 2017) consider this criterion to be fulfilled.

The current study therefore constitutes the first exploration of the content validity of the MDADI since its inception. The aim of this study was to carry out an investigation of UK clinicians' perceptions of the content validity of the MDADI with the aim of identifying areas for future investigation or development.

## METHODS

This study took the form of a qualitative exploration of UK speech and language therapists' (SLTs) perceptions of the content validity of the MDADI, via data generated by responses to an online questionnaire. Data presented and discussed in this study formed part of a mixed methods study which investigated the psychometric properties of the MDADI.

### Participants and procedure

Data were collected from a convenience sample ( $n = 31$ ) of UK-based SLTs via an online questionnaire. Participants were approached via professional networks and social media. Participants did not need to have experience of using the MDADI tool; however clinical experience of working with people with HNC was essential.

UK research approval was granted [IRAS REC no. 20/WM/0319] and research and development permission to carry out the study was sought and granted at both a local and national level (Health Research Authority, 2020).

Demographic data gathered on questionnaire participants were limited to years of clinical experience, location and MDADI usage patterns to ensure anonymity and are displayed in Table 1:

Questions on the MDADI were open-ended in nature to allow collection of qualitative data, with the response taking the format of a free-text comment box. The questionnaire was designed to collect data on individual MDADI items as well as the tool as a whole. Clinicians' experiences with use of the tool were elicited, considering overall validity, as well as clinical usability of the tool. An item asking for detail on comments made by patients to clinicians concerning the MDADI was also included following comments made during the questionnaire pilot stage by members of the study Patient & Public Involvement group.

TABLE 1 Participant demographic data.

Characteristic	Value
Subjects ( $n$ )	31
Location ( $n$ )	
England	19
Scotland	12
Mean experience working in HNC (years)	12.42
Range	1–34
Currently using the MDADI in clinical practice	
Yes (%)	64.52
No (%)	35.48
Timing of use of the MDADI ( $n$ )	
Pre-treatment	22
Directly post surgery	1
Immediately post treatment	1
3/52 post treatment	2
1/12 post treatment	1
6/52 post treatment	2
Every 6–8/52 during follow-up	1
3/12 post treatment	8
6/12 post treatment	13
ly post treatment	7
When clinically indicated	1
Before any block of therapy	2
After any block of swallow therapy	1
At time of SLT discharge/end of SLT episode of care	5
As indicated by any research study protocols	1

Abbreviations: HNC, head and neck cancer; MDADI, MD Anderson Dysphagia Inventory; SLT, speech and language therapy.

### Data analysis

Questionnaire data were downloaded from the online questionnaire platform and the free-text narrative data underwent a process of reflexive thematic analysis using Braun and Clarke's approach (Braun & Clarke, 2021). The majority of the data analysis was carried out by the first author, with 10% of the coding checked by the third author.

As the first author is a practising clinician who uses the MDADI tool in clinical and research work, their position as an 'insider researcher' when analysing the data (Braun & Clarke, 2021) was carefully considered, and care was taken throughout the process to minimise the potential for this to excessively influence data analysis. To facilitate this self-reflection and keep track of the analysis process, a 'reflexive diary' was kept throughout the process.

The narrative data generated by the questionnaire were analysed to produce codes. Then, through a process of review and repeat analysis of the codes, coherent themes

**TABLE 2** Summary of themes generated from thematic analysis.

	Theme name	Characteristics
1	The bigger picture of eating and drinking	Lack of focus in the MDADI about whether it is assessing swallowing, eating and drinking, other issues, or everything!
2	'not user-friendly'	How the MDADI is perceived to be negative, emotive and non-patient-centred
3	Excluded groups	Patient subgroups excluded by MDADI item wording or content
4	'not quite where we need it to be'—suggestions for change	Practical suggestions for changes and improvements to the tool that would make it more useful and patient-centred

Abbreviation: MDADI, MD Anderson Dysphagia Inventory.

were developed, refined and named. Four themes that had relevance to content validity were ultimately identified.

## RESULTS

Thematic analysis identified four themes which had relevance to content validity, summarised in Table 2.

### Theme 1: The bigger picture of eating and drinking

The MDADI was designed to assess 'dysphagia-specific' impact on patients' QoL; however, the questionnaire responses richly spoke to the fact that the tool frequently mixes swallowing impairment with other, more overarching aspects of eating and drinking, to the point that it is often not clear which aspect is being assessed with respect to impact on QoL. Respondent 19 described this as 'Poor wording-eating habits doesn't equate to swallowing'. Likewise Respondent 7 identified ambiguity in referring to 'eating' rather than swallowing: 'The phrase "eating habits" can be interpreted in many ways, and not necessarily relevant to swallowing. For example, some of my bariatric patients, or patients who wish to lose weight, will comment on this'.

A common theme throughout the dataset was the scope for issues other than oropharyngeal dysphagia to affect patients' responses to items. Respondent 4 described it thus: 'Most patients say my swallowing doesn't limit me—my issue is the pain/ saliva/ appetite/RT [radiotherapy] side effects'. Respondents also highlighted the impact den-

tal extractions, which is common practice prior to HNC treatment, can have on MDADI responses: 'If patients have had recent dental extractions this can influence their responses—sometimes need to guide them to think about oral intake prior to dental extractions' (Respondent 17).

### Theme 2: 'Not user-friendly'

Throughout the MDADI, respondents highlighted items that were felt to be ambiguous, requiring explanation, therefore being open to interpretation potentially affecting the 'user-friendliness' or validity of responses: 'Some questions are worded in a confusing way and the answers then need to be checked' (Respondent 7). Many respondents described how they had to 'step in' to help patients complete the tool due to ambiguously worded items: 'the wording of some questions is confusing therefore requires clarification from SLT' (Respondent 18). In addition, often it was not just concern about patients misunderstanding or being confused by items, but also SLTs themselves: 'Patients don't understand the question and nor do I' (Respondent 19).

### Theme 3: Excluded groups

Respondents identified subgroups of patients who would not be able to answer some, or any, of the MDADI items due to their health or social status at time of assessment.

Items that referred to 'eating out' were identified as potentially exclusory to patients of lower socioeconomic status who were not able to afford to do so, such as item 8 ('I do not go out because of my swallowing problem') which 'does not often highlight difficulties in our clinical caseload who often cannot afford to eat out' (Respondent 15).

Likewise, item 9 ('my swallowing difficulty has caused me to lose income') was felt to exclude patients who either could not work or who had retired. This was summarised by Respondent 12 who noted:

'I have had a number of respondents omitting this item or annotating it to say that they are not in employment. The predominance of over 60s or 65s in the HNC population tends to make this item slightly less relevant.'

Several items were also highlighted as being exclusory to patients who lived alone or were socially isolated, with the items' focus on friends, family and social interactions. These items were described as 'open to misinterpretation/non-representative answers as so many of our patients live alone/ do all the cooking



themselves/don't have anyone who cooks for them' (Respondent 17).

Significant issues throughout the tool were highlighted in terms of using the tool as a baseline measurement with patients prior to their HNC treatment, often before they have any symptoms of swallowing difficulty. Most items presume a swallowing problem and therefore clinicians have frequently experienced non-dysphagic patients not knowing how to answer an item, potentially skewing or invalidating their results; in addition to causing anxiety and trepidation about what might be on the horizon in terms of future treatment side effects. Respondent 17 summarised this concern: 'It can also concern people who do not have swallowing difficulties, as they worry that the questions are an indication of what they will face in future, for example, they might not be able to eat out, enjoy a meal with friends, be embarrassed about their eating etc.'

Finally, patients whose dysphagia is so severe that it has been recommended they be 'nil by mouth' (NBM) were highlighted as a group for whom responding to the MDADI would be extremely challenging. This cohort of patients must rely on non-oral, enteral nutrition to meet their nutritional requirements. A strong theme amongst respondents was that the MDADI was not appropriate to attempt in this situation and could not be ethically used with these patients: 'I wouldn't use this with someone who is NBM as a result of cancer/treatment as I feel it would be pretty insensitive' (Respondent 17). This then means that the group who potentially have the greatest reduction in dysphagia related QoL, due to not being able to eat or drink at all, are excluded from having this impact measured, as summarised by Respondent 20:

'I don't use it with patients who are nil by mouth as I feel it's unfair—they can't answer many of the items and it is upsetting. This is a big issue though as they may be that patient group whose quality of life is most impacted by their dysphagia!!'

#### Theme 4: 'Not quite where we need it to be'—Suggestions for change

Throughout the survey, respondents made comments on how the MDADI could be changed, with practical suggestions for rewording, modification, elision or removal of items. Several items were described as 'irrelevant' (Respondent 20), in addition many items were repetitive: 'several questions are very similar and would be good if they could be reduced' (Respondent 8). Respondents also remarked on the Likert scale response modality, voicing concerns that the descriptors were inappropriate: 'I don't think any-

**TABLE 3** COSMIN content validity rating results for the MDADI; Key: ± = indeterminate – = insufficient.

Content validity criteria	Overall rating
<b>Relevance</b>	
Are the included items relevant for the construct of interest?	±
Are the included items relevant for the target population of interest?	±
Are the included items relevant for the context of use of interest?	±
Are the response options appropriate?	–
Is the recall period appropriate?	+
<b>RELEVANCE RATING INCONSISTENT</b>	
<b>Comprehensiveness</b>	
Are all key concepts included?	–
<b>COMPREHENSIVENESS RATING INSUFFICIENT</b>	
<b>Comprehensibility</b>	
Are the PROM instructions understood by the population of interest as intended?	–
Are the PROM items and response options understood by the population of interest as intended?	–
Are the PROM items appropriately worded?	–
Do the response options match the question?	–
<b>COMPREHENSIBILITY RATING INSUFFICIENT</b>	

Abbreviations: COSMIN, COnsensus-based Standards for the selection of health Measurement Instruments; MDADI, MD Anderson Dysphagia Inventory; PROM, patient-reported outcome measure.

one has "no opinion" of the kind of questions that are being asked' (Respondent 14) and suggesting this response format potentially lead to an anchor effect: 'I find patients don't vary their answers between, for example, strongly agree versus agree and will stick with the same whichever they go with, right through' (Respondent 6).

An appetite for development and improvement of the MDADI was evident in the data: 'the MDADI could be adapted/updated to better reflect patient experiences particularly patients having treatment for HNC' (Respondent 10). Respondent 20 summarised the MDADI thus: 'Great potential but not quite where we need it to be to truly represent the impact of head and neck associated dysphagia'.

Following COSMIN guidance, the overall content validity of the MDADI was rated across the content validity domains defined by COSMIN: relevance, comprehensiveness and comprehensibility (Prinsen et al., 2018; Terwee et al., 2018). The results of this rating are illustrated in Table 3.



## DISCUSSION

Despite the MDADI's high profile within HNC research and practice, its content validity has been minimally appraised to date. This study provides the first qualitative data on the content validity of the MDADI from a clinician perspective and highlights issues with all three aspects of content validity as defined by COSMIN: relevance, comprehensiveness and comprehensibility (Prinsen et al., 2018; Terwee et al., 2018).

### Relevance

The HNC dysphagia literature highlights the existence of significant dysphagia-related QoL impact post treatment (Nund et al., 2014; Patterson, 2015) and therefore it is essential to have tools that can assess this and provide meaningful data. A major concern raised in this study is that the MDADI potentially lacks relevance in terms of its specific item content with respect to significant subgroups of people with HNC.

Data from this study highlighted that clinicians feel the MDADI is exclusory to several patient groups, most notably patients with NBM status who are dependent on tube-feeding due to the severity of their dysphagia. Patients with the most severe dysphagia also need assessment of their dysphagia-related QoL so their support and survivorship needs can be understood and addressed; a tool capable of assessing this is a necessity for clinical practice. There is a bioethical concern with PROMs that fail to meet the needs of more vulnerable subgroups, with PROMs in other clinical areas having been shown to be more challenging for example for older people or those with more severe symptoms (Hagell et al., 2009).

The subgroups identified in this study as being potentially excluded from validly completing the MDADI constitute important subsections of the HNC patient group, and the fact that the MDADI is inaccessible to them means a significant proportion of HNC patients are potentially excluded from measurement of their dysphagia-related QoL with this tool. This has significant implications for the use of the tool in both clinical and research settings. As the MDADI also assesses 'dysphagia-related quality of life' there may also be an issue with the validity of using it as a baseline, pre-treatment measure with patients who are not currently experiencing dysphagia.

### Comprehensiveness

The COSMIN criterion of comprehensiveness is that all key concepts should be included by a tool (Terwee et al., 2018). Theme 1 highlighted issues with the comprehensiveness of the MDADI. Specifically, the concern that the MDADI is not sufficiently clear about what it is assessing, due to a lack of definition of concept in terms of dysphagia versus the wider process of eating and drinking. This study indicates that clinicians find the wording of the MDADI inconsistent, interchanging the terms 'swallowing' and 'eating' without obvious rationale. It could be argued that the MDADI's scope is *too* comprehensive and needs to be reined in to focus specifically on dysphagia, or conversely not comprehensive enough, in that it does not give explicit reference to other swallowing-adjacent issues such as xerostomia or reduced dentition, which may be inseparable from patients' eating, drinking and swallowing experience (Bressan et al., 2017).

Inconsistencies in definition and delineation of what 'dysphagia' as an entity includes are evident in the published literature. Swallow physiology adjacent issues common in HNC such as dysgeusia and xerostomia may be grouped under the term 'dysphagia' as per Nund et al. (Nund et al., 2014) in their qualitative study investigating the lived experience of post-HNC dysphagia. Conversely, Ganzer et al. (Ganzer et al., 2015) use the term 'eating experience' in their literature review to encompass the complex, multifaceted physical, social and emotional impacts on eating, drinking and swallowing post HNC, incorporating 'dysphagia' as one element of the eating experience. Likewise, the recently developed Head and Neck Cancer Survivors' Assessment of Mealtimes tool (Chan et al., 2019) refers to 'mealtime experience' rather than swallowing alone, and qualitative, co-produced research carried out with people with HNC suggests 'altered eating' as a more appropriate umbrella term (Burgess Watson et al., 2018). It could be argued that the separation of swallow physiology from the bigger picture of eating and drinking is an artificial distinction; however, if this is the case terminology and focus should remain consistent within a tool, and the inconsistency in terminology in the MDADI at the very least needs to be addressed. This study has demonstrated that this inconsistency within the MDADI confuses users, disappoints clinicians and negatively impacts on its content validity.

This study evidences clinicians' concerns around ambiguity of wording in the tool, and that the literacy level of the MDADI may be too complex for many people with HNC, thus affecting their ability to complete it. This finding provides qualitative validation to Zraick et al.'s (Zraick et al., 2012) previous quantitative analysis of the 'readability' of the MDADI, which found the MDADI to be the 'most difficult to read' of all of the swallowing-related

### Comprehensibility

This study evidences clinicians' concerns around ambiguity of wording in the tool, and that the literacy level of the MDADI may be too complex for many people with HNC, thus affecting their ability to complete it. This finding provides qualitative validation to Zraick et al.'s (Zraick et al., 2012) previous quantitative analysis of the 'readability' of the MDADI, which found the MDADI to be the 'most difficult to read' of all of the swallowing-related



PROMs examined. Clinicians also voiced concerns that the Likert response modality of the tool had the potential to impact on response validity. Clinicians highlighted their experience of 'anchor effect' in patients' responses to the tool. 'Anchor effect' for Likert scales, where respondents are less likely to endorse the 'extreme' ends of the scale, thus affecting score validity, is a well-documented phenomenon (Bishop & Herron, 2015). Respondents also indicated that the MDADI is overly long, potentially containing redundant items; this is substantiated by Lin et al.'s (Lin et al., 2022) recent factor analysis of the MDADI which resulted in item reduction and the formation of a 5-item 'miniDADI'.

In summary, this study presents data that show UK clinicians have concerns about the content validity of the MDADI across all three COSMIN criteria of relevance, comprehensiveness and comprehensibility. This therefore supports a rating of the content validity of the MDADI as 'insufficient' using the COSMIN assessment criteria.

## Study limitations

### Lack of patient data

The depth of data generated from the clinicians produced relevant qualitative data on PROM content validity by including clinicians in tool evaluation. However, patient involvement in PROM development is strongly recommended in the literature (Addario et al., 2020) and the results of this study need to be considered with caution, as clinicians' proxy reporting of patients' experiences is not always reliable (Dunlop et al., 2022).

### Generalisability

Although circulated around networks accessible across the United Kingdom, questionnaire responses were recorded from 31 SLTs practising in England and Scotland only. This number of respondents is comparable to other practice-related survey-based research carried out with UK HNC SLTs (Roe et al., 2012). As the MDADI is an internationally used tool, and eating, drinking, swallowing and dysphagia are culturally sensitive, the results of this study may not be generalisable to other locations. Further triangulation with data from other countries is required to corroborate the data presented here.

### Reflexivity and potential for bias

The author is a practising HNC clinician who has used the MDADI with patients for many years. It could be argued therefore that she does not have a starting point of equipoise about the MDADI. Malterud (Malterud, 2001)

describes reflexivity as 'the knower's mirror'. During the analysis the author took steps to incorporate reflexivity and monitor for bias, using a reflective diary as a 'mirror' to monitor and manage the personal thoughts and reactions arising in response to the analysis process.

## CONCLUSION

The results of this study have shown that the content validity of widely used PROMs such as the MDADI cannot be assumed. We must reflect on and interrogate the tools we use in both clinical and research practice to ensure they are fit for purpose and add value to our patients' management.

Since its inception more than 20 years ago, the MDADI has been subject to surprisingly little scrutiny of many of its psychometric properties, even though it is one of the most well-used tools in HNC clinical and research practice. This study has highlighted issues with content validity from a clinician perspective that are salient and merit further investigation with service users. If they were to be corroborated this would constitute a significant challenge to the content validity of the MDADI, and thus the validity and reliability of MDADI data generated in clinical and research practice, indicating a pressing need for further development and amendment of the tool.

The MDADI is unique in its HNC-specific slant on dysphagia-related QoL assessment and has an established place in the world of HNC practice. However, this study suggests there is scope for further assessment and potentially amendment of the MDADI, to strengthen its content validity and support its continued use in HNC outcome evaluation.

## ACKNOWLEDGEMENT

This research did not receive any specific grant from funding agencies in the public, commercial or not-for-profit sectors.

## CONFLICT OF INTEREST STATEMENT

No conflicts of interest to declare

## DATA AVAILABILITY STATEMENT

The participants of this study did not give written consent for their data to be publicly available in a database format, so due to this ethical concern and the potential identifiability of participants who are drawn from a relatively small pool of eligible professionals, raw data is not available for sharing.

## REFERENCES

- Addario, B., et al. (2020) Including the patient voice in the development and implementation of patient-reported outcomes in cancer clinical trials. *Health Expectations*, 23(1), 41–51.



- Baijens, L.W.J., et al. (2021) European white paper: oropharyngeal dysphagia in head and neck cancer. *European Archives of Oto-Rhino-Laryngology*, 278(2), 577–616.
- Beitler, J.J., et al. (2010) Health literacy and health care in an inner-city, total laryngectomy population. *American Journal of Otolaryngology*, 31(1), 29–31.
- Bishop, P.A. & Herron, R.L. (2015) Use and misuse of the Likert item responses and other ordinal measures. *International Journal of Exercise Science*, 8(3), 297–302.
- Braun, V. & Clarke, V. (2021) *Thematic analysis: a practical guide*. London: SAGE Publications.
- Bressan, V., et al. (2017) The life experience of nutrition impact symptoms during treatment for head and neck cancer patients: a systematic review and meta-synthesis. *Supportive Care in Cancer*, 25(5), 1699–1712.
- Burges Watson, D.L., et al. (2018) Altered eating: a definition and framework for assessment and intervention. *BMC Nutrition*, 4(1), 14.
- Castellano, A. & Sharma, A. (2019) Systematic review of validated quality of life and swallow outcomes after transoral robotic surgery. *Otolaryngology - Head and Neck Surgery*, 161(4), 561–567.
- Chan, K.M.K., et al. (2019) Impact of head and neck cancer treatment on survivors' mealtime experience. *Laryngoscope*, 129(7), 1572–1578.
- Chen, A.Y., et al. (2001) The development and validation of a dysphagia-specific quality-of-life questionnaire for patients with head and neck cancer: the M. D. Anderson dysphagia inventory. *Archives of Otolaryngology - Head and Neck Surgery*, 127(7), 870–876.
- Connell, J., et al. (2018) The importance of content and face validity in instrument development: lessons learnt from service users when developing the Recovering Quality of Life measure (ReQoL). *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 27(7), 1893–1902.
- Dawson, C., Adams, J. & Fenlon, D. (2019) The experiences of people who receive swallow therapy after surgical treatment of head and neck cancer. *Oral Surgery, Oral Medicine, Oral Pathology and Oral Radiology*, 128(5), 456–463.
- Dunlop, E., et al. (2022) What matters to patients and clinicians when discussing the impact of cancer medicines on health-related quality of life? Consensus-based mixed methods approach in prostate cancer. *Supportive Care in Cancer*, 30(4), 3141–3150.
- Dwivedi, R.C., et al. (2010) Validation of the Sydney Swallow Questionnaire (SSQ) in a cohort of head and neck cancer patients. *Oral Oncology*, 46(4), e10–e14.
- Ganzer, H., et al. (2015) The eating experience after treatment for head and neck cancer: a review of the literature. *Oral Oncology*, 51(7), 634–642.
- Hagell, P., Reimer, J. & Nyberg, P. (2009) Whose quality of life? Ethical implications in patient-reported health outcome measurement. *Value in Health: The Journal of the International Society for Pharmacoeconomics and Outcomes Research*, 12(4), 613–617.
- Health Research Authority. (2020) *UK policy framework for health and social care research*. London: Health Research Authority.
- Hutcheson, K.A., et al. (2016) What is a clinically relevant difference in MDADI scores between groups of head and neck cancer patients? *Laryngoscope*, 126(5), 1108–1113.
- Hutcheson, K.A., et al. (2017) Dynamic Imaging Grade of Swallowing Toxicity (DIGEST): scale development and validation. *Cancer*, 123(1), 62–70.
- Jabbour, J., et al. (2017) Education and support needs in patients with head and neck cancer: a multi-institutional survey. *Cancer*, 123(11), 1949–1957.
- Khan, M.K., et al. (2015) Comparing the Performance Status Scale and MD Anderson Dysphagia Inventory as swallowing outcome measures in head and neck cancer: a prospective cohort study. *Clinical Otolaryngology*, 40(4), 321–326.
- Lin, D.J., et al. (2022) Psychometric properties of the MDADI—A preliminary study of whether less is truly more? *Dysphagia*, 37(2), 323–332.
- Malterud, K. (2001) Qualitative research: standards, challenges, and guidelines. *Lancet*, 358(9280), 483–488.
- Martino, R., et al. (2021) The PRO-ACTIVE trial protocol: a randomized study comparing the effectiveness of PROphylACTic swallow InterVention for patients receiving radiotherapy for head and neck cancer. *BMC cancer*, 21(1), 1100.
- Mehanna, H.M., et al. (2017) Phase III randomised controlled trial (RCT) comparing alternative regimens for escalating treatment of intermediate and high-risk oropharyngeal cancer (CompARE). *Journal of Clinical Oncology*, 35(15\_suppl), TPS6091–TPS6091.
- Mendez, A., et al. (2020) Development of a patient-centered functional outcomes questionnaire in head and neck cancer. *JAMA Otolaryngology-Head & Neck Surgery*, 146(5), 437–443.
- Nichols, A.C., et al. (2020) Treatment de-escalation for HPV-associated oropharyngeal squamous cell carcinoma with radiotherapy vs. trans-oral surgery (ORATOR2): study protocol for a randomized phase II trial. *BMC Cancer*, 20(1), 125.
- Nund, R., et al. (2014) The lived experience of dysphagia following non-surgical treatment for head and neck cancer. *International Journal of Speech-Language Pathology*, 16(3), 282–289.
- Ojo, B., et al. (2012) A systematic review of head and neck cancer quality of life assessment instruments. *Oral Oncology*, 48(10), 923–937.
- Owadally, W., et al. (2015) PATHOS: a phase II/III trial of risk-stratified, reduced intensity adjuvant treatment in patients undergoing transoral surgery for Human papillomavirus (HPV) positive oropharyngeal cancer. *BMC Cancer*, 15(1), 602.
- Patel, D.A., et al. (2017) Patient-reported outcome measures in dysphagia: a systematic review of instrument development and validation. *Diseases of the Esophagus*, 30(5), 1–23.
- Patterson, J.M., et al. (2015) Head and neck cancer patients' perceptions of swallowing following chemoradiotherapy. *Supportive Care in Cancer*, 23(12), 3531–3538.
- Pedersen, A., et al. (2016) Swallowing outcome measures in head and neck cancer—How do they compare? *Oral Oncology*, 52: 104–108.
- Petkar, I., et al. (2016) DARS: a phase III randomised multicentre study of dysphagia- optimised intensity- modulated radiotherapy (Do-IMRT) versus standard intensity- modulated radiotherapy (S-IMRT) in head and neck cancer. *BMC Cancer*, 16(1), 770.
- Prinsen, C.A.C., et al. (2018) COSMIN guideline for systematic reviews of patient-reported outcome measures. *Quality of Life Research*, 27(5), 1147–1157.
- Roe, J.W., et al. (2012) Assessment and management of dysphagia in patients with head and neck cancer who receive radiotherapy in the United Kingdom—a web-based survey. *Oral Oncology*, 48(4), 343–348.



- Speyer, R., et al. (2014) Psychometric properties of questionnaires on functional health status in oropharyngeal dysphagia: a systematic literature review. *BioMed Research International*, 2014. 458678.
- Terwee, C.B., et al. (2018) COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. *Quality of Life Research*, 27(5), 1159–1170.
- Thomson, D.J., et al. (2023) TORPEdO: a phase III trial of intensity-modulated proton beam therapy versus intensity-modulated radiotherapy for multi-toxicity reduction in oropharyngeal cancer. *Clinical and Translational Radiation Oncology*, 38, 147–154.
- Timmerman, A.A., et al. (2014) Psychometric characteristics of health-related quality-of-life questionnaires in oropharyngeal dysphagia. *Dysphagia*, 29(2), 183–198.
- Verdonck-de Leeuw, I., et al. (2022) European Head and Neck Society recommendations for head and neck cancer survivorship care. *Oral Oncology*, 133: 106047.

- Zraick, R.I., Atcherson, S.R. & Ham, B.K. (2012) Readability of patient-reported outcome questionnaires for use with persons with swallowing disorders. *Dysphagia*, 27(3), 346–352.

**How to cite this article:** Toft, K., Best, C. & Donaldson, J. (2024) Assessment of patients with head and neck cancer using the MD Anderson Dysphagia Inventory: Results of a study into its comprehensiveness, comprehensibility and relevance to clinical practice. *International Journal of Language & Communication Disorders*, 11111. <https://doi.org/10.1111/1460-6984.13026>



