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Background

Analysing and enhancing the MD Anderson dysphagia inventory (MDADI)

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 Dysphagia, or difficulty swallowing, is a highly prevalent symptom of head and neck cancer (HNC) and has a marked impact on patients' quality of life (QoL)

- Measurement of dysphagia-related QoL through patient reported outcome measures (PROMs) is a key part of HNC clinical and research practice
- Currently the only tool that caters to this need is the MD Anderson Dysphagia
 Inventory (MDADI) (Chen et al., 2001)

The MDADI

•A PROM that assesses dysphagia-related QoL in HNC – the only tool of its kind

•Written questionnaire format, 20 items with Likert scale responses

•2 sides of A4, 'college-level' literacy (Zraick etal 2012)

Methods

• This study followed a pragmatic, mixed methods approach to evaluate the MDADI

Qualitative

- Narrative data from a convenience sample of 31 UK Speech & Language Therapists (SLTs) were gathered via an online survey, focusing on content validity and clinical utility of the MDADI
- Data were analysed using a reflexive thematic analysis approach

Quantitative

- MDADI data collected between 2016-2021 from 302 patients with HNC treated in NHS Lothian, at pre-treatment and 6 months posttreatment, were analysed using Item Response Theory mathematical models
- Structural validity, internal consistency and the presence of Differential Item Functioning (DIF), i.e. bias, in specific tool items were analysed

• Minimal information available about patient contribution to development

•Widely used in HNC research and clinical practice

stronaly disoare

strongly disagree

strongly disagree

•No previous research has explored its content validity or clinical utility

MD Anderson Dysphagia Inventory

This questionnaire asks for your views about your swallowing ability. This information will help us understand how you feel about swallowing. The following statements have been made by people who have problems with their swallowing. Some of the statements may apply to you. Please read each statement and circle the response which best reflects your experience in the past week.

 My swallow 	ing ability limits n	ny day to day activities		
Strongly agree	ogree	no opinion	disagree	strongly disagree
2. 1 am embar	rassed by my eati	ng habits		
Strongly agree	ogree	no opinion	disagree	strongly disagree
3. People have	e difficulty cookin	g for me		
Strongly agree	agree	no opínion	disagree	strongly disagree
4. Swallowing	is more difficult a	t the end of the day		
Strongly agree	agree	no opinion	disagree	strongly disagree

I am upset by my swallowing problem

I do not go out because of my swallowing proble

My swallowing difficulty has caused me to lose incom

Swallowing takes great effort

MD Anderson Dysphagia Inventory

10. It takes me	longer to eat bec	ause of my swallowing p	problem	
Strongly agree	agree	no opinion	disagree	strongly disagree
11. People ask	me 'why can't you	u eat that?'		
Strongly agree	ogree	no opinion	disagree	strongly disagree
12. Other peop	le are irritated by	my eating problem		
Strongly agree	ogree	no opinion	disagree	strongly disagree
13. I cough wh	en I try to drink lic	quids		
Strongly agree	agree	no opinion	disagree	strongly disagree
14. My swallow	ving problems limi	it my personal and socia	ıl life	
Strongly agree	agree	no opinion	disagree	strongly disagree
15. I feel free t	o go out to eat wi	th my friends, neighbou	rs, relatives	
Strongly agree	ogree	no opinion	disagree	strongly disogree
16. I limit my fo	ood intake becaus	e of my swallowing diffi	culty	
Strongly agree	agree	no opinion	disagree	strongly disagree
17. I cannot ma	aintain my weight	because of my swallow	ing problem	
Strongly agree	agree	no opinion	disagree	strongly disagree
18. I have low :	telf esteem becau	se of my swallowing pro	meide	
Strongly agree	agree	no opinion	disagree	strongly disagree
19. I feel that I	am swallowing a	huge amount of food		
Strongly agree				strongly disagree

Results

•	Content validity	of the tool was	s highlighted as a	a major concern	by clinicians:
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Issues with content validity	Characteristics
Potential item bias	Patient subgroups were identified who might respond differently to specific MDADI items
The bigger picture of eating and drinking	There is a lack of focus in the MDADI about whether it is assessing swallowing, eating and drinking, other issues, or everything!
"not user-friendly"	The MDADI is perceived to be negative, emotive and non- patient-centered
Excluded groups	Patient subgroups are excluded by MDADI item wording or content, for example patients who are Nil By Mouth

The clinical utility of the MDADI was also found to be problematic:
 Length, literacy level, layout and response format of the tool were felt to negatively impact on its ease of use for both patients and clinicians

Implications for practice

- Although a tool specific to assessing dysphagia related QoL has great relevance for clinical practice, this study suggests there is a pressing need for either amendment of the MDADI, or development of a new tool that could take its place
- The issues identified with the MDADI mean that the information the tool produces may be invalid and unreliable
- The Southeast Scotland SLT Cancer Network will review its routine use of the MDADI in light of these results

HNC related dysphagia has a significant and lasting impact on service users.

We need outcomes tools that are not only psychometrically robust,

- Quantitative analysis showed:
 - Structural validity and internal consistency to be acceptable but that the MDADI has a ceiling effect when used at a pre-treatment point
 - DIF, i.e. bias, in several items for the variables of
 - age
 - sex
 - socioeconomic status

but also practicably usable with strong relevance to patients and clinicians.

Tools should produce meaningful data that can be used to drive and improve care at an individual patient level.

It is hoped that this study can form the first step towards improving the validity and clinical utility of the MDADI.

References

CHEN, A. Y., FRANKOWSKI, R., BISHOP-LEONE, J., HEBERT, T., LEYK, S., LEWIN, J. & GOEPFERT, H. 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. Arch Otolaryngol Head Neck Surg, 127, 870-6.

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, 346-52.