



What Are We Really Measuring? A Content Comparison of Swallowing Outcome Measures for Head and Neck Cancer Based on the International Classification of Functioning, Disability and Health (ICF)

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Abstract

A combination of outcome measures are required to provide important information on the physiological profile and associated impact of dysphagia in head and neck cancer (HNC). Choosing the most appropriate tool can be a difficult and time-consuming process. The aim of this study was to identify and then compare the content of tools commonly used to assess swallowing post HNC care using the International Classification of Functioning Disability and Health (ICF) as a reference. A literature audit of 11 databases was conducted for relevant articles published between January 2004 and June 2017 and total of 502 papers met the inclusionary criteria. These papers were audited and 27 tools were identified which met the study criteria. The meaningful concepts contained in each tool were mapped to the ICF. Within the 27 tools, 898 meaningful concepts were identified and matched to 60 ICF categories. The most frequently matched ICF categories related to body functions, while comparatively few concepts matched to activity and participation and environmental factors. This study has identified that a large number of tools are currently being used in HNC research to measure swallowing outcomes. The sheer number of tools available to explore dysphagia post HNC highlights the lack of a uniform approach to outcome measurement which limits the potential to compare and combine research studies in order to strengthen treatment evidence. There is a need to develop an international consensus for a core outcome set of swallowing related measures, that capture the holistic impact of dysphagia, for HNC.

Keywords Deglutition · Deglutition disorders · Head and neck cancer · ICF · Outcome measures

Introduction

The physiological profile of dysphagia associated with head and neck cancer (HNC) is well established in the literature [1]. Dysphagia is a multifactorial condition that can have serious medical, psychosocial and existential effects on the everyday lives of HNC survivors [1–4]. As a result, measuring dysphagia-related outcomes throughout the patient journey is a mainstay of both research and clinical practice

in HNC [5–7]. An array of validated and reliable tools have been developed to measure dysphagia and its impact. However, different tools may fit different purposes and often more than one tool is required to measure the multifactorial and complex nature of dysphagia in HNC.

Numerous tools have been developed to address swallowing outcomes [8–10], and therefore, selecting the most appropriate tool or group of tools specifically for HNC care can be an arduous and time-consuming process. Furthermore, systematic reviews of the tools currently used to measure and monitor dysphagia (without any specific population focus) have noted that many have low levels of validity and reliability [8–10]. Whilst selecting measures based on their psychometric properties is a critical consideration, the selection of the most appropriate tools for a particular clinical or research context is heavily influenced by the content

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or aspect of dysphagia that is under investigation. In HNC care, it is recognised that tumour presence and treatment factors have differential impacts on swallowing specifically [1, 11–13] and the individual as a whole. Hence, research of the past decade has highlighted the importance of considering dysphagia and its impacts from more than simply an impairment focus [4, 14, 15].

It is also well accepted now that measures of dysphagia in HNC should include clinician-rated measures of swallow function and patient-reported outcomes [16]. It is to be anticipated then that the tools used to assess swallowing and its impact specifically in the area of HNC care will differ with regard to the nature of administration, as well as the depth and breadth of concepts targeted. Instrumental assessments such as videofluoroscopic swallowing studies and fiberoptic endoscopic swallowing studies directly observe anatomy and physiologic function during swallowing and numerous tools have been developed and validated in order to report and interpret instrumental assessments. These instruments are completed by clinicians and are often considered gold standard as they do not include subjective factors related to patient-reported functions. Numerous validated instruments are also available to assess patient functioning following HNC treatment. These measures can be either clinician-rated and based on either non-instrumental assessments (e.g., clinical assessment) or global indicators of functional status (e.g., diet level and gastrostomy dependence), or patient-rated to assess an individual's perspective of their functioning post-treatment.

To accurately compare the contents of various tools used in HNC care, a framework that provides a comprehensive and standardised terminology is required. The International Classification of Functioning, Disability and Health (ICF), endorsed by the World Health Organization (WHO) [17], was developed from a bio-psycho-social model and provides a universal language of functioning and health and serves as a common reference in which various health and health-related concepts can be linked [17]. The ICF describes functioning in two parts, namely (1) functioning and disability; and (2) contextual factors. Functioning and disability is comprised of two components including *body functions and body structures*, as well as *activities and participation*. Contextual factors are made up of *environmental factors*, which refer to the physical, social, and attitudinal environment, as well as *personal factors*, which refers to the background of an individual's life and living and are made up of features of the individual that are not part of a health condition [17].

Each of these components are comprised of several domains and within these domains are categories that can be used to describe, in detail, an individual's health and health-related states using specific category codes [17]. The ICF consists of over 1400 categories that are represented by alphanumeric codes in which the letters b, s, d, and e are

used to indicate body functions, body structures, activities and participation, and environmental factors, respectively [17]. These letters are then followed by a numeric code that represents the chapter or domain followed by additional coding. In the case of dysphagia, difficulties with chewing would be represented by the body functions code *b5102—chewing*, reduced social participation would be coded to activities and participation *d9205—socializing*, and the need to modify food and fluids would be coded as an environmental factor *e1100—food*. Personal factors include features such as gender, race, profession, and coping style. Personal factors are not currently coded in the ICF [17].

It has previously been established that the ICF can be used successfully to represent the complex and multifaceted impact of dysphagia in HNC [18]. Furthermore, the ICF has been used successfully in content comparisons of tools used for measuring other health states, including quality of life in HNC [19]; obesity [20], musculoskeletal disorders [21] and hearing impairment [22]. A content comparison of outcome tools being used to measure and monitor dysphagia in HNC is necessary to assess the current scope of available tools and identify any gaps in the ICF concepts not covered by these existing dysphagia tools. In addition, such analysis can assist clinicians and researchers to undertake more considered decisions regarding the selection of the most appropriate tool for a particular research or clinical context. Therefore, the aim of the current study is to comprehensively identify the tools commonly used to measure swallowing in the HNC patient population and examine the contents of these tools using the ICF as a reference.

Methods

This study was conducted in two stages. The first stage involved conducting a literature audit to identify and select tools commonly used in the published literature to measure swallowing in HNC patients. In the second stage, the contents of the tools identified were examined and mapped to the ICF framework to register an inventory of available tools and identify any gaps in content specific to swallowing.

Stage 1: Literature Audit

Search Strategy

The literature audit of 11 databases (PubMed, Medline, CINAHL, Web of Science, Scopus, Embase, PsycINFO, the Cochrane Central Register of Controlled Trials, Joanna Briggs Institute of Evidence-Based Practice, Allied and Complementary Medicine Database, and the Database of Abstracts of Review of Effects) was conducted by two members of the research team. The purpose was to identify

articles that were published in peer-reviewed journals between January 2004 and June 2017. The main search terms included head and neck neoplasms and deglutition disorders. Additional search terms are listed in the supplementary material.

Study Selection

A rigorous consensus process was conducted in which all titles, abstracts, and full-text were reviewed at least twice by two different members of the research team. The research team consisted of a panel of seven internationally recognised experts in dysphagia management in HNC, each with a track record of publications in this field. Any discrepancies in ratings were resolved by consensus with a third-rater. Citations were included if they presented first-hand data concerning people with HNC and included any measure of swallowing or swallowing related outcomes. Citations were excluded if they were: (1) not related to HNC (i.e., citations related to esophageal, thyroid or skin cancer); (2) review papers, case reports (single participant), case studies (< 10 participants), educational papers, conference abstract, economic evaluations; (3) involved pediatric patients (< 18 years old); (4) an animal study; (5) published prior to January 2004; (6) not explicitly related to swallowing outcomes; (7) in a language other than English.

Tool Selection

A full review of each accepted article was conducted by all members of the research team and information regarding tools used to measure swallowing outcomes were extracted. Tools were initially accepted if they met the following criteria: (a) tools that were specific to swallowing in HNC; (b) tools that were specific to swallowing but not necessarily HNC; and (c) tools that were specific to HNC and contained a minimum of one question related to swallowing. Once this initial set of tools was identified, a secondary set of inclusion criteria were applied. To give meaningful information on swallowing and swallowing-related outcomes, it is important that the psychometric properties of a tool have been examined [10]. Hence, tools were only accepted if they had at least some published data supporting their psychometric properties. In addition, in order to be considered “common”, tools were required to have been cited by at least two different author groups, demonstrating that groups other than those who developed the tool have commenced using it in research. This methodology and criteria for inclusion is consistent with previous studies that have examined the contents of outcome measures against the ICF [19]. An audit of 20% of the abstracts and full-text data extraction was conducted by a second rater and discrepancies were resolved by consensus.

Stage 2: ICF Coding Process

Meaningful concepts within each tool that specifically addressed swallowing and/or eating were identified and mapped to the ICF using the established coding rules [23, 24]. Some key points from the coding rules include: (1) link meaningful concepts to the most precise ICF category (2) if a single item contains more than one concept, each concept should be linked (3) do not use so-called ‘other specified’ or ‘unspecified’ ICF categories (identified by the final code 8 and 9), and (4) personal factors are assigned the code pf. As an example, item one of the Eating Assessment Tool (EAT-10) [25] was coded as follows: ‘My swallowing problem has caused me to lose weight’, the meaningful concepts ‘swallowing problem’ and ‘lose weight’ would be linked to b5105 ‘swallowing’ and b530 ‘weight maintenance’, respectively. In addition, if an item within the tool did not relate directly to swallowing, then the meaningful concepts within that item were not mapped. For example, the first item of the Functional Assessment of Cancer Therapy—Head and Neck 4 (FACT H&N) [26] ‘I have a lack of energy’ does not explicitly relate to swallowing and therefore the meaningful concepts within this item were not mapped. The ICF codes representing the concepts contained in each tool formed the basis of the content comparison and analysis.

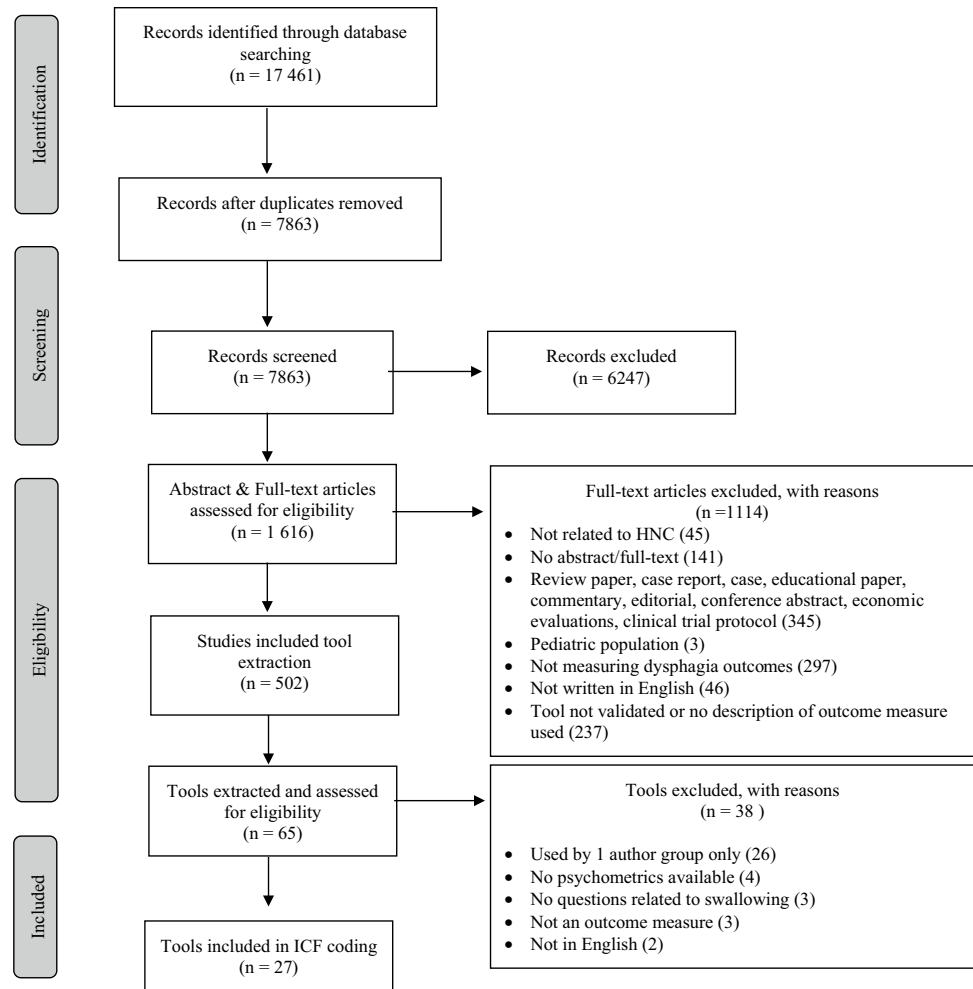
This coding process was conducted independently by two members of the research team experienced with the ICF and conducting ICF coding. The reliability of the mapping process was evaluated by computing percentage exact agreement and by calculating kappa coefficients based on the two independent mapping versions of each tool. The kappa analysis was performed with SPSS version 24 (<https://www.ibm.com/au-en/products/spss-statistics>). Where any discrepancies were noted in the coding of the two-raters, these were discussed and a consensus decision reached.

Results

Stage 1: Literature Audit

The electronic literature audit yielded 17,461 citation hits (Fig. 1). After removing duplicates, 7863 citations remained. As a result of the title screen, a further 6247 citations were removed. The remaining 1616 citations were evaluated based on their abstract and full-text against the inclusion/exclusion criteria and relevant tools were identified in the accepted articles. A total of 502 studies were included and 65 tools extracted. Each tool was then screened against the secondary criteria and 27 met the study’s full set of inclusion criteria. Table 1 provides an overview of the characteristics of each tool. Of the 27 tools included, 14 were clinician-rated tools and 13 were patient-rated tools.

Fig. 1 PRISMA flow diagram detailing search strategy and selection criteria



Stage 2: ICF Coding Process

Coding Agreement

Table 2 shows the evaluation of the coding procedure by percent exact agreement and kappa coefficients. Percent exact agreement and estimated kappa values ranged from 52.94 to 100 and 0.5 to 1.00, respectively, indicating a wide range in agreement between the two coders, depending on the instrument. The main reason for this finding was that the established coding rules were not always sufficient when coding swallowing measures and allowed too much individual interpretation. There were also ambiguities regarding descriptions of specific category codes in the ICF.

Identification of Meaningful Concepts within Tools

A total of 898 meaningful concepts related to dysphagia were identified across the 27 tools. Out of the 898 meaningful concepts, 836 (93%) were linked to 60 different ICF categories. Twenty-seven of the 60 ICF categories were

represented by the ‘body functions’ component, five by the ‘body structures’ component, 19 by the activities and participation component, and nine by ‘environmental factors’. The specific codes listed by component (body functions, body structures, activities and participation and environmental factors) are detailed below and in Tables 3, 4, 5, 6, 7 and 8. A small number (62 concepts, 7%) of all meaningful concepts could not be linked to the ICF. Of these 32 items were identified as personal factors and 30 were other meaningful concepts pertaining to swallowing/eating including ‘control’, ‘enjoyment’, ‘pleasure’, and ‘under strictly defined conditions’. As these concepts cannot be classified in the current version of the ICF, this information was not able to be coded.

ICF Coding: Body Functions and Body Structures Component

Body functions refer to the physiological functions of the body systems and body structures refer to the anatomical parts of the body [17]. Concepts related to body functions were represented in the majority of tools ($n=23$), whereas

Table 1 Summary of selected tools

Abbreviation of question-naire	Aim	Number of items/domains	Time for completion (min)	Respondent	Scaling/rating	Time frame for answer	Availability
AusTOMs Swallowing Scale [27]	Measure speech pathology outcomes related to swallowing	4 domains	5–10	Clinician	6 pt scale	Present time	Purchase
CTCAE [28]	Grade acute and late toxicity	124	15–20	Clinician	5 pt scale	Present time	Free
DHI [29]	Measure the emotional, physical and functional effects of dysphagia on quality of life	25	10	Self	3 pt scale 1–7 pt scale	Present time	Free
DOSS [30]	Severity of dysphagia based on instrumental assessment	1	10	Clinician	7 severity levels	Requires instrumental assessment	Free
EAT-10 [25]	Assess symptom severity, quality of life, and treatment efficacy for people with dysphagia	10	5	Self	0–4 pt scale 2 open ended questions	Present time	Free
EORTC QLQ-C30 [31]	Assess quality of life of cancer patients	30	10	Self	4–7 pt scale	7 days	On request
EORTC QLQ H&N35 [32]	Assess quality of life of HNC patients in conjunction with general cancer	35	10	Self	4 pt scale	7 days	On request
FACT-H&N [26]	Measure quality of life and patient perception of treatment-related side effects in HNC	39	10	Self	5 pt scale	7 days	Free
FOIS [33]	Document change in functional oral intake of food and liquid	1	< 5	Clinician	7 levels	Present time	Free
FOSS [34]	Assess severity of dysphagia	1	5–10	Clinician	6 levels	Present time	Free
HNCI [35]	Measure HNC health status and capture patient perspective of functional status	30	10	Self	5 pt scale	4 weeks	Free
LENT-SOMA [36]	Assess late toxicity	75 (Head and Neck)	20	Clinician	Grade 1–4	Present time	Free
MASA-C [37]	Assess swallowing performance in HNC	27	10–15	Clinician	Various scales	Present time	Free

Table 1 (continued)

Abbreviation of question-naire	Aim	Number of items/domains	Time for completion (min)	Respondent	Scaling/rating	Time frame for answer	Availability
MBS-Imp [38]	Quantify swallowing impairment based on modified barium swallow	17	15	Clinician	Range from 3–5	Requires modified barium swallow	Purchase
MDADI [39]	Measure impact of dysphagia on QOL of patients with HNC	20	10	Self	5 pt scale	7 days	Free
OPSE [40]	Measure the degree of safety and efficient of a swallow	7	15	Clinician	Formula	Requires modified barium swallow	Free
PAS [41]	Rate penetration and/or aspiration on modified barium swallow	1	5	Clinician	8 levels	Requires modified barium swallow	Free
PSS-HN [42]	Evaluate performance in areas of functioning most likely affected by head and neck cancer and its treatment	21	<5	Clinician via interview	5–11 pt scale	Present time	Free
RBHOMS [43]	Identify and monitor difficulties with everyday performance of swallowing function	1	<5	Clinician	10 levels	Present time	Free
RTOG Acute and Late [44]	Scoring acute and late toxicity following radiotherapy	17 (acute) 17 (late)	10–15	Clinician	5 pt scale	Present time	Free
SSQ [45]	Assess the severity of oral and pharyngeal dysphagia in patients with dysphagia	17	10	Self	100 mm visual analog scale 5 pt scale	Present time	Free
SWAL-QOL [46]	Measure quality of life outcomes in dysphagia	44	15	Self	5 pt scale Yes/No Open-ended	Varies between 7 days to 1 month	On request
UMHNQOL [47]	Assess HNC related functional status and wellbeing	28	10	Self	5 pt scale Yes/no Short answer	4 weeks	Free
UW-QOL V4 [48]	Provides data on physical, functional, emotional and quality of life of HNC patient	12	10	Self	5 pt scale	7 days	Free

Table 1 (continued)

Abbreviation of question-naire	Aim	Number of items/domains	Time for completion (min)	Respondent	Scaling/rating	Time frame for answer	Availability
VHNCSS [49]	Monitor prevalence and severity of oral health outcomes	50	<10	Self	11 pt scale	7 days	Free
WST [50]	Screen for presence of dysphagia	1	5	Clinician	3 parameters	Present time	N/A
XRQOL [51]	Measure the impact of salivary gland dysfunction on oral health related quality of life	15	10	Self	5 pt scale	7 days	Free

AusTOMs Australian Therapy Outcome Measure, *CTCAE* Common Terminology Criteria for Adverse Events, *DHI* Dysphagia Handicap Index, *DOSS* Dysphagia Outcome Severity Scale, *EAT-10* eating assessment tool, *EORTCQLQ C30* European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Cancer 30, *EORTCQLQ H&N35* European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Head & Neck 35, *FACT-H&N* Functional Assessment of Cancer Therapy Head & Neck, *FOIS* Functional Oral Intake Scale, *FOSS* Functional Outcome Swallowing Scale, *HNCI* Head and Neck Cancer Inventory, *LENT-SOMA* late effects normal tissue subjective, objective, management, analytic, *MASA-C* Mann Assessment of Swallowing Ability-Cancer, *MBSImp* Modified Barrium Swallow Impairment Profile, *MDADI-M.D.* Anderson Dysphagia Inventory, *OPSE* oropharyngeal swallowing efficient, *PAS* Penetration Aspiration Scale, *PSS-HN* Performance Status Scale for Head and Neck Cancer, *RBHOMS* Royal Brisbane Hospital Outcome Measure for Swallowing, *RTOG Acute and Late* radiation therapy oncology group acute and late, *SSQ* Sydney Swallow Questionnaire, *SWAL-QOL* Swallowing Quality of Life Scale, *UMHNCQOL* University of Michigan Quality of Life, *UWQOLv4* University of Washington Quality of Life Version 4, *VHNCSS* Vanderbilt Head and Neck Cancer Symptom Survey, *WST* water swallow test, *XRQOL* xerostomia-related quality of life

Table 2 Percent exact agreement and Kappa coefficients for the coding procedure

Tool	Percent exact agreement	Kappa coefficient
AusTOMs—Swallowing Scale [27]	84.62	0.89
CTCAE [28]	75	0.82
DHI [29]	92.31	0.94
DOSS [30]	88.89	0.93
EAT-10 [25]	80	0.87
EORTC QLQ-C30 [31]	100	1.00
EORTC QLQ H&N35 [32]	75	0.84
FACT-H&N [26]	75	0.86
FOIS [33]	60	0.77
FOSS [34]	63.64	0.75
HNCI [35]	87.50	0.92
LENT-SOMA [36]	87.50	0.92
MASA-C [37]	52.94	0.60
MBSImp [38]	100	1.00
MDADI [39]	56.25	0.55
OPSE [40]	50	0.73
PAS [41]	100	1.00
PSS-HN [42]	100	1.00
RBHOMS [43]	60	0.67
RTOG Acute & Late [44]	81.82	0.94
SSQ [45]	54.55	0.69
SWAL-QOL [46]	81.82	0.81
UMHNSQOL [47]	61.54	0.72
UW-QOL V4 [48]	100	1.00
VHNCSS [49]	72.22	0.76
WST [50]	50	0.73
XRQOL [51]	70	0.74

See Table 1 for abbreviations

relatively few tools covered concepts related to body structures ($n=4$) (Table 3 and 4). The most frequently occurring body functions codes across tools included b5105—swallowing ($n=23$), b450—additional respiratory functions ($n=11$), b5104—salivation ($n=11$), b5102—chewing ($n=10$), and b530 weight maintenance functions ($n=9$). The MASA-C was found to cover the largest number of body functions and body structures codes for clinician-rated tools ($n=14$), whereas the VHNS covered the largest number of body functions and body structures codes for patient-rated tools ($n=13$). Tools which did not cover any components pertaining to body functions were the FOIS, PSS-HN, and EORTCQLQ-C30.

ICF Coding: Activities and Participation Component

The ICF defines activities as the execution of a task and participation as an individual's involvement in a life situation

[17]. Twenty-four tools included at least one concept that was able to be mapped to the activities and participation component. In total, 19 activity and participation codes were utilised across tools. The most frequently represented activities and participation codes included d550—eating ($n=23$), d560—drinking ($n=6$), and d9205—socializing ($n=5$). The AusTOMs ($n=7$) [25] and the SWAL-QOL ($n=11$) provide the greatest coverage of activities and participation for clinician and patient-rated tools, respectively. The activities and participation component was not covered at all in a number of tools such as the MBSImp.

ICF Coding: Environmental Factors Component

Environmental factors include the physical, social, and attitudinal environment in which people live and conduct their lives [17]. The mapping exercise was only able to link nine environmental factor codes with the meaningful concepts identified across tools. Despite the limited number of codes, 23 tools included at least one unique concept that was mapped to environmental factors. The most common environmental factor codes across tools included e1100—food ($n=22$) and e1151 ($n=14$) assistive products and technology for personal use in daily living. The RBHOMS ($n=4$), the EORTC QLQ-HN35 ($n=4$) and the MDADI ($n=4$) capture the largest number of environmental factors. Environmental factors were not covered by MBSImp, OPSE, PAS, or WST.

Discussion

As per prior systematic reviews of general dysphagia tools [8–10], the results of the current study demonstrate that a large number of tools are being used in research to measure and describe dysphagia in HNC care. Such diversity has important implications for research and the ability to combine and compare outcomes across studies. Further to this, this study demonstrates that the majority of tools used to measure and describe dysphagia in HNC focus largely on the physiological aspects of swallowing, followed by activities and participation, with only a few categories of environmental factors represented. This is consistent with the state of the current literature which has a greater focus on describing the assessment and management of the physiological changes to the swallow mechanism as a result of HNC and its treatment. Over the last decade, however, there has been an increasing interest in studying the broad-ranging impact of dysphagia in HNC beyond the physiological changes to the swallow. Therefore, to accurately capture the profile of dysphagia and its associated impact on the lives of our patients, we need to consider which tools or combination of tools will provide a more holistic picture of patient functioning.

Table 3 Frequency of ICF categories from the component “body structures” and “body functions” represented in the clinician-rated tools

ICF component and categories	AusTOMs	CTCAE	DOSS	FOIS	FOSS	LENT-SOMA	MASA-C	MBS-Imp	OPSE	PAS	PSS-HN	RBHOMS	RTOG acute and late	WST
Total	5	9	4	0	10	4	14	4	1	2	0	6	6	1
Body structures														
s320 Structure of mouth							x							
s3202 Structure of palate							x							
s3203 Structure of tongue							x							
s3204 Structure of lips							x							
Body functions														
b1302 Appetite		x												
b152 Emotional functions	x													
b1521 Regulation of emotion	x													
b250–b279 Additional sensory functions				x										
b250 Taste function		x				x							x	
b255 Smell function							x							
b265 Touch function		x												
b2801 Pain in body part		x			x									x
b440 Respiration functions				x										
b450 Additional respiratory functions			x				x			x				
b460 Sensations associated with cardiovascular and respiratory functions		x												
b510 Ingestion functions			x					x						
b5100 Sucking	x													
b5102 Chewing			x											
b5103 Manipulation of food in the mouth	x													
b5104 Salivation		x											x	
b5105 Swallowing	x	x	x										x	
b5106 Regurgitation and vomiting									x				x	
b530 Weight maintenance functions														
b535 Sensations associated with the digestive system		x												
b545 Water, mineral and electrolyte balance functions														
b5450 Water balance		x												
b730 Muscle power functions														
b7602 Coordination of voluntary movements														

See Table 1 for abbreviations

“x” represents the presence of the ICF code within the corresponding tool

Table 4 Frequency ICF categories from the component “body structures”, and “body functions” represented in the patient-rated tools

ICF Component and categories	DHI	EAT-10	EORTC QLQ-C30	EORTC QLQ-HN35	FACT-H&N	HNCI	MDADI	SSQ	SWAL-QOL	UM HNQOL	UW-QOL V4	VHNS	XRQOL
Total	7	4	0	2	1	4	5	6	8	8	4	13	2
Body structures													
s320 Structure of the mouth												x	
s3200 Teeth					x					x		x	
Body functions													
b1266 Confidence							x						
b1302 Appetite									x	x			
b152 Emotional functions	x					x	x						
b250 Taste function										x			x
b255 Smell function												x	
b270 Sensory functions related to temperature and other stimuli												x	
b280 Sensation of pain		x											
b2801 Pain in body part										x			
b440 Respiration functions	x								x				
b450 Additional respiratory functions	x	x					x						
b460 Sensations associated with cardiovascular and respiratory functions	x			x							x		
b510 Ingestion functions													
b5102 Chewing						x							
b5103 Manipulation of food in mouth													
b5104 Salivation	x									x			
b5105 Swallowing	x	x		x									x
b5106 Regurgitation and vomiting													
b530 Weight maintenance functions	x	x					x						

See Table 1 for abbreviations

“x” represents the presence of the ICF code within the corresponding tool

Table 5 ICF categories from the component “activities and participation” represented in the clinician-rated tools

ICF component and categories	AusTOMs	CTCAE	DOSS	FOIS	FOSS	LENT-SOMA	MASA-C	MBS-Imp	OPSE	PAS	PSS-HN	RBHOMS	RTOG Acute and Late	WST
Total	7	4	1	1	1	1	1	0	0	0	2	1	1	0
d Activities and participation		x												
d177 Making decisions	x													
d5 Self-care		x											x	
d550 Eating	x	x	x	x	x	x	x				x	x		
d560 Drinking	x	x												
d760 Family relationships	x													
d810–d839 Education	x													
d850 Remunerative employment	x													
d9205 Socializing	x													

See Table 1 for abbreviations

“x” represents the presence of the ICF code within the corresponding tool

It is beyond the scope of the current study to make recommendations regarding which tool or combination of tools should be used to measure dysphagia outcomes in HNC. However, it is apparent from the large number of tools identified in this study that the research regarding dysphagia in HNC lacks a uniform approach to outcome measurement. As a result, the research outcomes across studies will continue to be difficult to compare and combine, thus limiting the potential to strengthen treatment evidence through meta-analysis and data pooling. Previously, Chera et al. [52] recognised the need to establish a core set of patient-reported symptoms in HNC treatment trials. Twelve HNC core symptoms were recommended including swallowing, oral pain, skin changes, dry mouth, dental health, opening mouth/trismus, taste, excess/thick saliva, shoulder disability/motion, voice/hoarseness, social domain, and functional domain [52]. Whilst this is an important first step regarding consistency of outcome measurement across trials, limited information is provided regarding dysphagia and its impact on patient functioning. To determine whether dysphagia treatments in HNC are effective, a consensus regarding a minimum core set of outcome measures must be established.

Hutcheson and colleagues raised this issue in their development of the Dynamic Imaging Grade of Swallowing Toxicity (DIGEST) [53]. Recognising the issues of combining swallowing outcome measures into simple toxicity gradings for use in large scale clinical trials, the DIGEST was developed as a companion to the widely used CTCAE and provides a modified barium swallow (MBS) graded measure of pharyngeal dysphagia [52]. At the time the current study was conducted, this tool was not published by other groups, however, this type of simple, singular measure may help address the challenges of comparing dysphagia outcomes across clinical trials in the future. Naturally though, selecting a single measure such as the DIGEST may help assist researchers to track and compare impairment-based changes, with impacts to activity and participation and environmental impacts failing to be captured.

Research has found that dysphagia has a pervasive effect on the everyday lives of HNC patients affecting activities of daily living, changes to social networks and support as well as the need to develop coping strategies and seek out professional support [54]. To better understand the functional impact of dysphagia in HNC from the patients’ perspective, Nund et al. mapped the patients’ perspectives to the ICF [18]. Though that study was limited to people treated non-surgically, the results indicated that body functions, activities and participation, and environmental factors were almost equally important to people with dysphagia in HNC. Therefore, selecting tools which only focus on the physiological and anatomical assessment of the swallow are likely to inadequately capture the impacts and concerns of this population [18]. It is, therefore, suggested that clinicians and

Table 6 Frequency of ICF categories from the component “activities and participation” represented in the patient-rated tools

ICF Component and categories	DHI	EAT-10	EORTC QLQ-C30	EORTC QLQ-HN35	FACT-H&N	HNCI	MDADI	SSQ	SWAL-QOL	UM HNQOL	UM	UW-QOL V4	VHNCSS	XRQOL
Total	2	3	1	1	2	2	6	1	11	1	1	1	2	1
d230 Carrying out daily routine							x							
d240 Handling stress and other psychological demands									x					
d2401 Handling stress		x												
d330 Speaking									x					
d350 Conversation														
d550 Eating	x	x	x	x	x	x	x	x	x	x	x	x	x	x
d560 Drinking					x				x				x	
d630 Preparing meals						x			x					
d760 Family relationships														
d7500 Informal relationships with friends														
d8 Major life areas														
d850 Remunerative employment							x							
d870 Economic self-sufficiency														
d920 Recreation and leisure							x							
d9205 Socializing	x	x					x							

See Table 1 for abbreviations

“x” represents the presence of the ICF code within the corresponding tool

Table 7 Frequency of ICF categories from the component “environmental factors” represented in the clinician-rated tools

ICF component and categories	AusTOMs	CTCAE	DOSS	FOIS	FOSS	LENT-SOMA	MASA-C	MBS-Imp	OPSE	PAS	PSS-HN	RBHOMS	RTOG Acute and Late	WST
Total	3	2	2	2	2	3	0	0	0	0	3	4	3	0
e1100 Food	x	x	x	x	x	x					x	x	x	
e1101 Drugs						x							x	
e1151 Assistive products and technology for personal use in daily living	x	x	x	x	x	x					x	x	x	
e3 Support and relationships	x		x							x		x		
e355 Health professionals														x

See Table 1 for abbreviations
 “x” represents the presence of the ICF code within the corresponding tool

Table 8 Frequency of ICF categories from the component “environmental factors” represented in the patient-rated tools

ICF Component and categories	DHI	EAT-10	EORTC QLQ-C30	EORTC QLQ-HN35	FACT-H&N	HNCI	MDADI	SSQ	SWAL-QOL	UM HNQOL	UW-QOL V4	VHNCSS	XRQOL
Total	3	2	1	4	1	2	4	1	2	2	1	2	2
e1100 Food	x	x		x	x	x	x	x	x	x	x	x	x
e1101 Drugs	x	x											
e1151 Assistive products and technology for personal use in daily living	x					x			x	x		x	
e3 Support and relationships			x										x
e310 Immediate family				x			x						
e315 Extended family				x									
e320 Friends													
e325 Acquaintances, peers, colleagues, neighbours and community members							x						

See Table 1 for abbreviations
 “x” represents the presence of the ICF code within the corresponding tool identification

researchers consider selecting tools that will provide pertinent information on body functions, activities and participation and environmental factors as they relate to swallowing.

However the challenge, as highlighted by the current study findings, is that very few tools cover more than one ICF domain equally. Therefore, if we are to embrace a more holistic perspective of dysphagia, more than one tool is needed. Even with a multi-tool approach, there are current gaps in the aspects of dysphagia appropriately captured by current existing tools. Whilst there are tools that exist which cover body functions and activities and participation equally (e.g., MDADI and SWAL-QOL), there are a lack of tools available that evaluate environmental factors related to dysphagia [55]. To address this gap, Chan et al. recently developed and validated the Head and Neck Cancer Survivor's Assessment of Mealtimes (HNSAM) [15]. The HNSAM was developed from the HNC survivors perspective and classified against the ICF framework. Environmental factors are clearly identified in the tool and incorporate a number of areas, such as support and attitudes of family, friends, and health professionals, that are missing from the current range of patient-reported outcome measures. Though the HNSAM showed initial validity and reliability, the tool was developed in Chinese and the authors of the HNSAM have identified the need for psychometric testing in English [15].

Heterogeneity in outcome measurement is not unique to dysphagia in HNC. The Core Outcome Measures in Effectiveness Trials (COMET) initiative, launched in 2010, brings together researchers interested in the development and application of 'core outcome sets'. The COMET databases (see <http://www.comet-initiative.org>) currently lists 1125 references of planned, ongoing and completed work in core outcome sets, however, there are no listed projects relating to dysphagia. As highlighted by the results of the current study, the number of tools in use, and the diversity of concepts addressed by each tool highlights that leaders in this area also need to embrace the concepts of developing a core outcome measure set for HNC. Whilst the existence of a core set does not preclude the use of other tools for other research purposes, it will help establish a common language through which researchers and clinicians can document the widespread and long-term impacts of dysphagia on patient survivorship. This is an area for future work.

It is acknowledged that limitations exist in the current study. First, it is acknowledged that the inter-rater reliability of ICF coding was quite variable. Though the majority of ratings demonstrated moderate to almost perfect agreements, a small number of ratings had weak levels of agreement. As reported in previous studies, the coding rules were not always sufficient when coding the swallowing measures and allow for too much individual interpretation [22]. In addition, there was some discussion between

the two researchers regarding the latent interpretation of several statements in order to be correctly linked. Latent interpretation is common in content analysis and refers to the underlying meaning of a concept [20]. This factor was especially relevant for the concepts swallowing, eating, and drinking. For example, item 13 on the MDADI states "I cough when I try to drink liquids". In this case, one researcher coded the concepts "cough"—b450, "drink" d560, and "liquids" e1100 whilst the other coded "cough"—b450, "drink" b5105 (swallowing), and "liquids" e1100. The two researchers interpreted the meaning of "drink" differently and had further discussions regarding whether this item on the MDADI was really asking about the "impairment" or the "activity". Ultimately the researchers met on several occasions to discuss the latent interpretations of these items and consensus was reached during those meetings. It is further acknowledged that only a minimum standard was set for the psychometric properties of the tools included in this review. The authors are very aware of the differences between the level and rigor of psychometric evaluations conducted across the various tools included in this review and encourage researchers and clinicians to also consider the psychometric evaluations when selecting tools for their context. Finally, it is acknowledged that newer tools have been established in the last few years, particularly in the domain of image processing for instrumental assessments. Though these tools did not meet the criteria for inclusion in the current study, they should be considered when defining a core set of outcomes in the future.

In conclusion, this study has confirmed the diversity in outcome measures currently in use to document dysphagia and its impacts following HNC. It has provided insights regarding the depth, breadth, and precision of concepts covered, and demonstrated areas that few tools currently capture, such as environmental factors. This information can be used by clinicians and researchers when selecting instruments for use in dysphagia management to ensure that the instrument chosen covers the area of most concern/interest. Given the large number of measures, there is a need to establish a core outcome set of outcome measures for dysphagia in HNC. In the meantime, researchers and clinicians need to consider not only the psychometric properties, but also the content covered by the tools, to determine whether the tools will provide an accurate and holistic picture of patient functioning post HNC care.

Compliance with Ethical Standards

Conflict of interest The authors declared that they have no conflict of interest.

References

- Wall LR, Cartmill B, Ward EC, Hill AJ. Physiological changes to the swallowing mechanism following (chemo)radiotherapy for head and neck cancer: a systematic review. *Dysphagia*. 2013;28:481–93. <https://doi.org/10.1007/s00455-013-9491-8>.
- Hunter KU, et al. Aspiration pneumonia after chemo-intensity-modulated radiation therapy of oropharyngeal carcinoma and its clinical and dysphagia-related predictors. *Head Neck*. 2014;36:120–5. <https://doi.org/10.1002/hed.23275>.
- Lazarus CL, et al. Functional outcomes and quality of life after chemoradiotherapy: baseline and 3 and 6 months post-treatment. *Dysphagia*. 2014;29:365–75. <https://doi.org/10.1007/s00455-014-9519-8>.
- Nund RL, Ward EC, Scarinci NA, Cartmill B, Kuipers P, Porceddu SV. The lived experience of dysphagia following non-surgical treatment for head and neck cancer. *Int J Speech Lang Pathol*. 2014;16:282–9. <https://doi.org/10.3109/17549507.2013.861869>.
- Cancer Council Australia. Optimal care pathway for people with head and neck cancers. <https://www.cancer.org.au/ocp>. Accessed 9 Dec 2018.
- National Institute for Health and Care Excellence (2018) Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over. NICE GUIDELINE 36. <https://www.nice.org.uk/guidance/ng36>. Accessed 9 Dec 2018.
- Nekhlyudov L, et al. Head and neck cancer survivorship care guideline: American Society of Clinical Oncology clinical practice guideline endorsement summary. *J Oncol Pract*. 2018;14:167–71. <https://doi.org/10.1200/JOP.2017.029041>.
- Martino R, et al. A systematic review of current clinical and instrumental swallowing assessment methods. *Curr Phys Med Rehabil Rep*. 2013;1:267–79. <https://doi.org/10.1007/s40141-013-0033-y>.
- Speyer R, et al. Psychometric properties of questionnaires on functional health status in oropharyngeal dysphagia: a systematic literature review. *Biomed Res Int*. 2014;2014:1–11. <https://doi.org/10.1155/2014/458678>.
- Timmerman AA, Speyer R, Heijnen BJ, Klijn-Zwinjnenberg IR. Psychometric characteristics of health-related quality-of-life questionnaires in oropharyngeal dysphagia. *Dysphagia*. 2014;29:183–98. <https://doi.org/10.1007/s00455-013-9511-1>.
- Barnhart M, Robinson R, Simms V, Ward EC, Cartmill B, Chandler S, Smee R. Treatment toxicities and their impact on oral intake following non-surgical management for head and neck cancer: a 3 year longitudinal study. *Support Care Cancer*. 2018;26:2341–51. <https://doi.org/10.1007/s00520-018-4076-6>.
- Moroney LB, et al. Helical IMRT with concurrent chemotherapy for oropharyngeal SCC: a prospective investigation of acute swallowing and toxicity patterns. *Head Neck*. 2018;40:1955–66. <https://doi.org/10.1002/hed.25182>.
- van der Molen L, van Rossum MA, Ackerstaff AH, Smeele LE, Rasch CR, Hilgers FJ. Pretreatment organ function in patients with advanced head and neck cancer: clinical outcome measures and patients' views. *BMC Ear Nose Throat Disord*. 2009. <https://doi.org/10.1186/1472-6815-9-10>.
- Patterson JM, McColl E, Wilson J, Carding P, Rapley T. Head and neck cancer patients' perceptions of swallowing following chemoradiotherapy. *Support Care Cancer*. 2015;23:3531–8. <https://doi.org/10.1007/s00520-015-2715-8>.
- Chan KMK, Chan HKW, Siu JYL, Pu D, Nund RL, Ward EC. Impact of head and neck cancer treatment on survivors meal-time experience. *Laryngoscope*. 2018. <https://doi.org/10.1002/lary.27501>.
- Hutcheson KA, Lewin JS. Functional assessment and rehabilitation: how to maximize outcomes. *Otolaryngol Clin N Am*. 2013;46:657–70. <https://doi.org/10.1016/j.otc.2013.04.006>.
- World Health Organization. International Classification of Functioning, Disability and Health. Geneva: World Health Organization; 2001.
- Nund RL, Ward EC, Scarinci NA, Cartmill B, Kuipers P, Porceddu SV. Application of the International Classification of Functioning, Disability and Health (ICF) to people with dysphagia following non-surgical head and neck cancer management. *Dysphagia*. 2014;29:692–703. <https://doi.org/10.1007/s00455-014-9563-4>.
- Tschiesner UM, Rogers SN, Harreus U, Berghaus A, Cieza A. Content comparison of quality of life questionnaires used in head and neck cancer based on the international classification of functioning, disability and health: a systematic review. *Eur Arch Otorhinolaryngol*. 2008;265:627–37. <https://doi.org/10.1007/s00405-008-0641-9>.
- Stucki A, Borchers M, Stucki G, Cieza A, Amann E, Ruof J. Content comparison of health status measures for obesity based on the international classification of functioning, disability and health. *J Obes*. 2006;30:1791–9. <https://doi.org/10.1038/sj.jco.0803335>.
- Brockow T, Cieza A, Kuhlow H, Sigl T, Franke T, Harder M, Stucki G. Identifying the concepts contained in outcome measures of clinical trials on musculoskeletal disorders and chronic widespread pain using the International Classification of Functioning, Disability and Health as a reference. *J Rehabil Med*. 2004;44:30–6. <https://doi.org/10.1080/16501960410015371>.
- Granberg S, Moller K, Skagerstrand A, Moller C, Danermark B. The ICF Core Sets for hearing loss: researcher perspective, part II: linking outcome measures to the International Classification of Functioning, Disability and Health (ICF). *Int J Audiol*. 2014;53:77–87. <https://doi.org/10.3109/14992027.2013.858279>.
- Cieza A, Brockow T, Ewert T, Amman E, Kolleritis B, Chatterji S, Ustun TB, Stucki G. Linking health-status measurements to the international classification of functioning, disability and health. *J Rehabil Med*. 2002;34:205–10.
- Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B, Stucki G. ICF linking rules: an update based on lessons learned. *J Rehabil Med*. 2005;37:212–8. <https://doi.org/10.1080/16501970510040263>.
- Belafsky PC, Mouadeb DA, Rees CJ, Pryor JC, Postma GN, Allen J, Leonard RJ. Validity and reliability of the eating assessment tool (EAT-10). *Ann Otol Rhinol Laryngol*. 2008;117:919–24. <https://doi.org/10.1177/000348940811701210>.
- List MA, D'Antonio LL, Cella DF, Siston A, Mumby P, Haraf D, Vokes E. The Performance Status Scale for Head and Neck Cancer patients and the Functional Assessment of Cancer Therapy-Head and Neck Scale. A study of utility and validity. *Cancer*. 1996;77:2294–301.
- Perry A, Skeat J. Australian therapy outcome measures (AusTOMs) for speech pathology. Victoria: La Trobe University; 2004.
- Trotti A, Colevas AD, Setser A, Rusch V, Jaques D, Budach V, Rubin P. CTCAE v3.0: development of a comprehensive grading system for the adverse effects of cancer treatment. *Semin Radiat Oncol*. 2003;13:176–81. [https://doi.org/10.1016/S1053-4296\(03\)00031-6](https://doi.org/10.1016/S1053-4296(03)00031-6).
- Silbergleit AK, Schultz L, Jacobson BH, Beardsley T, Johnson AF. The Dysphagia Handicap Index: development and validation. *Dysphagia*. 2012;27:46–52. <https://doi.org/10.1007/s00455-011-9336-2>.
- O'Neil KH, Purdy M, Falk J, Gallo L. The dysphagia outcome and severity scale. *Dysphagia*. 1999;14:139–45. <https://doi.org/10.1007/PL00009595>.
- Bjordal K, et al. Development of a European Organization for Research and Treatment of Cancer (EORTC) questionnaire

- module to be used in quality of life assessments in head and neck cancer patients. *Acta Oncol.* 1994;33:879–85.
32. Bjordal K, et al. Quality of life in head and neck cancer patients: validation of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-H&N35. *J Clin Oncol.* 1999;17:1008–19. <https://doi.org/10.1200/JCO.1999.17.3.1008>.
 33. Crary MA, Mann GD, Groher ME. Initial psychometric assessment of a functional oral intake scale for dysphagia in stroke patients. *Archiv Phys Med Rehabil.* 2005;86:1516–20. <https://doi.org/10.1016/j.apmr.2004.11.049>.
 34. Salassa JR. A functional outcome swallowing scale for staging oropharyngeal dysphagia. *Dig Dis.* 1999;7:230–4. <https://doi.org/10.1159/000016941>.
 35. Funk GF, Karnell LH, Christensen AJ, Moran PJ, Ricks J. Comprehensive head and neck oncology health status assessment. *Head Neck.* 2003;25:561–75. <https://doi.org/10.1002/hed.10245>.
 36. Ho KF, Farnell DJ, Routledge JA, Burns MP, Sykes AJ, Slevin NJ, Davidson SE. Comparison of patient-reported late treatment toxicity (LENT-SOMA) with quality of life (EORTC QLQ-C30 and QLQ-H&N35) assessment after head and neck radiotherapy. *Radiother Oncol.* 2010;97:270–5. <https://doi.org/10.1016/j.radonc.2010.01.017>.
 37. Carnaby GD, Crary MA. Development and validation of a cancer-specific swallowing assessment tool: MASA-C. *Support Care Cancer.* 2014;22:595–602. <https://doi.org/10.1007/s00520-013-2011-4>.
 38. Martin-Harris B, et al. MBS measurement tool for swallow impairment–MBSImp: establishing a standard. *Dysphagia.* 2008;23:392–405. <https://doi.org/10.1007/s00455-008-9185-9>.
 39. Chen AY, Frankowski R, Bishop-Leone J, Hebert T, Leyk S, Lewin J, Goepfert H. 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.* 2001;127:870–6.
 40. Rademaker AW, Pauloski BR, Logemann JA, Shanahan TK. Oropharyngeal swallow efficiency as a representative measure of swallowing function. *J Speech Hear Res.* 1994;37:314–25.
 41. Rosenbek JC, Robbins JA, Roecker EB, Coyle JL, Wood JL. A penetration-aspiration scale. *Dysphagia.* 1996;11:93–8.
 42. List MA, D’Antonio LL, Cella DF, Siston A, Mumby P, Haraf D, Vokes E. The Performance Status Scale for Head and Neck Cancer patients and the Functional Assessment of Cancer Therapy-Head and Neck Scale: a study of utility and validity. *Cancer.* 1996;77:2294–301.
 43. Ward EC, Conroy AL. Validity, reliability and responsivity of the Royal Brisbane Hospital outcome measure for swallowing. *Asia Pacific J Speech Lang Hear.* 1999;4:109–29. <https://doi.org/10.1179/136132899805577051>.
 44. Cox JD, Stetz J, Pajak TF. Toxicity criteria of the Radiation Therapy Oncology Group (RTOG) and the European organization for research and treatment of cancer (EORTC). *Int J Radiat Oncol Biol Phys.* 1995;31:1341–6. [https://doi.org/10.1016/0360-3016\(95\)00060-C](https://doi.org/10.1016/0360-3016(95)00060-C).
 45. Dwivedi RC, et al. Validation of the Sydney Swallow Questionnaire (SSQ) in a cohort of head and neck cancer patients. *Oral Oncol.* 2010;46:e10–4. <https://doi.org/10.1016/j.oraloncology.2010.02.004>.
 46. McHorney CA, Robbins J, Lomax K, Rosenbek JC, Chignell K, Kramer AE, Bricker DE. The SWAL-QOL and SWAL-CARE outcomes tool for oropharyngeal dysphagia in adults: III documentation of reliability and validity. *Dysphagia.* 2002;17:97–114. <https://doi.org/10.1007/s00455-001-0109-1>.
 47. Terrell JE, Nanavati KA, Esclamado RM, Bishop JK, Bradford CR, Wolf GT. Head and neck cancer-specific quality of life. *Arch Otolaryngol Head Neck Surg.* 1997;123:1125–32.
 48. Rogers SN, Gwanne S, Lowe D, Humphris G, Yueh B, Weymuller EA Jr. The addition of mood and anxiety domains to the University of Washington quality of life scale. *Head Neck.* 2002;24:521–9. <https://doi.org/10.1002/hed.10106>.
 49. Murphy BA, et al. Reliability and validity of the Vanderbilt Head and Neck Symptom Survey: a tool to assess symptom burden in patients treated with chemoradiation. *Head Neck.* 2010;32:26–37. <https://doi.org/10.1002/hed.21143>.
 50. Patterson JM, Hildreth A, McColl E, Carding PN, Hamilton D, Wilson JA. The clinical application of the 100 mL water swallow test in head and neck cancer. *Oral Oncol.* 2011;47:180–4. <https://doi.org/10.1016/j.oraloncology.2010.11.020>.
 51. Henson BS, Inglehart MR, Eisbruch A, Ship JA. Preserved salivary output and xerostomia-related quality of life in head and neck cancer patients receiving parotid-sparing radiotherapy. *Oral Oncol.* 2001;37:84–93. [https://doi.org/10.1016/S1368-8375\(00\)00063-4](https://doi.org/10.1016/S1368-8375(00)00063-4).
 52. Chera BS, et al. Recommended patient-reported core set of symptoms to measure in head and neck cancer treatment trials. *J Natl Cancer Inst.* 2014;106:dju127–dju131. <https://doi.org/10.1093/jnci/dju127>.
 53. Hutcheson KA, et al. Dynamic Imaging Grade of Swallowing Toxicity (DIGEST): scale development and validation. *Cancer.* 2017;123:62–70. <https://doi.org/10.1002/cncr.30283>.
 54. Bressan V, Bagnasco A, Aleo G, Catania G, Zanini MP, Timmins F, Sasso L. The life experience of nutrition impact symptoms during treatment for head and neck cancer patients: a systematic review and meta-synthesis. *Support Care Cancer.* 2017;25:1699–712. <https://doi.org/10.1007/s00520-017-3618-7>.
 55. Threats TT. Use of the ICF in dysphagia management. *Semin Speech Lang.* 2007;28:323–33. <https://doi.org/10.1055/s-2007-986529>.

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