
Article:
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Do the existing quality of life tools appropriately measure oral health related quality of life in head and neck cancer? A scoping review

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Abstract

Background: Head and neck cancers and their respective treatments have a profound impact on the quality of life. Many oropharyngeal and oral cancers likely have implications for oral health-related quality of life (OHRQoL). Research investigating tools to measure OHRQoL is lacking.

Method: We conducted a scoping review to ascertain the available tools for measuring OHRQoL in head and neck cancer patients. The primary objective was to compile a summary of the existing tools and determine their completeness, validity, and reliability.

Results: The literature search yielded 1239 articles. Thirty-one studies were included in the review. Multiple tools were identified. None of the tools assessed all potential OHRQoL impacts, and none had undergone comprehensive testing using a range of assessments. The majority of the tools did not adhere to published guidance, with only the EORTC tools citing methodological guidance in their survey tool development protocols. All tools achieved recommended readability scores in English.

Discussion: Due to methodological flaws in the evidence base, it was not possible to definitively establish the completeness of any available tool. There was discordance between tools regarding the relevant OHRQoL impacts. Several tools failed to assess accepted domains of OHRQoL, calling into question their concordance with the construct of OHRQoL. In addition, there was a lack of adherence to published standards regarding both the construction and testing methods for quality of life instruments. Studies reporting on OHRQoL in head and neck cancer may, therefore, not comprehensively assess the actual impacts of the disease and its treatment.

Introduction

Mouth and oropharyngeal cancer is the 16th most common cancer globally.[1] All the treatment modalities for HNC can profoundly impact patients' daily function and quality of life (QoL). These treatments can result in altered structure, mobility, function and appearance of oro-facial structures.

There is increasing research and clinical focus towards the importance of survivorship and QoL. Numerous studies have investigated methods to improve QoL by minimising the oral side effects of HNC treatment, and by rehabilitating as early as possible.[2–4] Despite the increasing focus on QoL, the currently reported treatment outcomes focus on functional oral outcomes, such as chewing, rather than all domains of oral health related quality of life (OHRQoL).[5,6]

There is no consensus on the optimal tool for assessing OHRQoL in HNC patients. Whilst quantitative methods can assess tool validity and reliability, they may miss important aspects of the patient experience. Thus, quantitative *and* qualitative techniques are needed for a comprehensive evaluation. A qualitative scoping review of these methods is suggested. This contrasts with a pre-existing published article focussing on validation of published tools.[5]

Aims

This scoping review aims to systematically investigate the evidence base regarding OHRQoL reporting tools in HNC.

The objectives of this scoping review are to:

1. Identify patient reporting tools for OHRQoL for use following curative treatment for HNC patients
2. Ascertain which, if any, instruments are validated to investigate OHRQoL in HNC
3. Ascertain which items and domains of OHRQoL each tool assesses and whether *any* tool comprehensively assesses all potential items and all domains of OHRQoL
4. Determine areas where further research is required to better understand the oral health experiences of HNC patients

The primary research question has been developed utilizing the PCC (patient/population, concept, context) framework, which is recommended by the Joanna Briggs Institute[7]: the population (patients treated for HNC), the concept (oral health related quality of life), and the context (curative treatment). The primary research question is: Are any of the QoL tools reported by the literature appropriate, valid, or reliable for measuring OHRQoL in patients treated curatively for head and neck cancer?

Methodology

The methodological development is outlined in the published development protocol.[8] This guided selection of a scoping review combined with a narrative synthesis as an appropriate method to provide a holistic analysis

of the available tools and evidence base.[9] In accordance with the Arskey and O'Malley framework, as well as guidance from the Joanna Briggs Institute, we did not conduct a formal quality appraisal of the literature but rather performed a qualitative analysis of the methodological quality of studies.[10]

The literature search used pre-determined search criteria (Table 1). Information specialists supported the development of the search strategy, including search piloting and cross-referencing. As OHRQoL is an emerging concept in HNC research, not all studies investigating the patient's oral health experience explicitly describe OHRQoL. Therefore, the search strategy included terms directly and indirectly related to OHRQoL.

Patient experience	OHRQoL	Disease (Cancer)
• Appearance OR *esthetic • Chewing OR eating OR oral function • Speech OR speaking OR phonation OR vocal* OR phonetic* • Swallow* • Pain OR tenderness or sinusitis • Dry mouth OR xerostomia OR • Teeth OR denture	• (Oral health OR dental health) AND • (patient report* OR experience OR qualitative OR thematic OR phenominolog* OR interview OR questionnaire) QoL tools: • "EORTC" OR "UW QoL" OR "UW-QoL" OR "UWQoL" OR "University of Washington" OR "QL-5D-5L" OR "QL 5D 5L" OR "PCI" OR "patient concerns inventory" OR "patient reported" OR "Vanderbilt" OR "VHNSS" OR "LENT-SOMA" OR "LENT SOMA" OR "LENTSOMA" OR "QoL" OR "QoL" OR "quality adjusted life year*" OR "QALY*" OR "LORQ" OR "Liverpool Oral Health" OR "QLQ-OH*"	• Cancer OR malignan* OR neoplas* OR tumour OR squamous cell OR SCC AND • head OR neck OR oral OR tongue OR mouth OR maxilla* OR mandib* OR salivary OR gingiv*

Table 1 – Summary of the search terms utilised. These were modified based on the requirements of the search engine to maximise the quality of the search (for example, in the use of Boolean search terms)

Relevant Mesh terms and ICD-10 codes were included. The following databases were assessed: National Library of Medicine (via PubMed), Scopus, and OVID, incorporating the Embase, PsycINFO, CENTRAL, and Cochrane databases.

A grey literature search was performed.

Inclusion criteria:

1. **Population**: studies which develop or test tools to measure QoL for patients treated curatively for HNC
2. **Concept**: studies reporting on the construction of, or results from, a tool used to report on OHRQoL
3. **Context**: studies investigating cases of curative treatment of HNC only
4. Primary research studies only including qualitative, quantitative and mixed research methodologies
5. No date restriction

Exclusion criteria:

1. Not reporting on curatively treated HNC
2. Not developing/testing QoL tools
3. Not published in the English language

Search results were screened iteratively (title, then abstract, then full text) with blinding, using Rayyan AI[11]. Data extraction was performed using Microsoft® Excel . The domains measured were informed by the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) and the Evaluating the Measurement of Patient-Reported Outcomes (EMPRO) tools. Each tool was also analysed for readability using published methods[12] (Flesch-Kincade) to assess compliance with recommendations for public publications.[12]

The data synthesis summarized the literature and focused on the theoretical constructs underpinning QoL tools to determine their scientific robustness and the need for further research. We assessed the construction and testing of the tools, stakeholder involvement and the external validity of methods.

Results

Literature search and screening

The search identified 1239 articles, resulting in 534 articles following de-duplication. There was 96% agreement between reviewers regarding article inclusion. All conflicts over article inclusion were resolved by clarifying the study population and methodology. We identified 392 articles (73.4%) focused on QoL but did not develop/test a QoL tool. Article screening is summarised in Figure 1. Study authors were contacted where required (e.g. abstract/poster) however, two papers were not retrieved.[13,14]

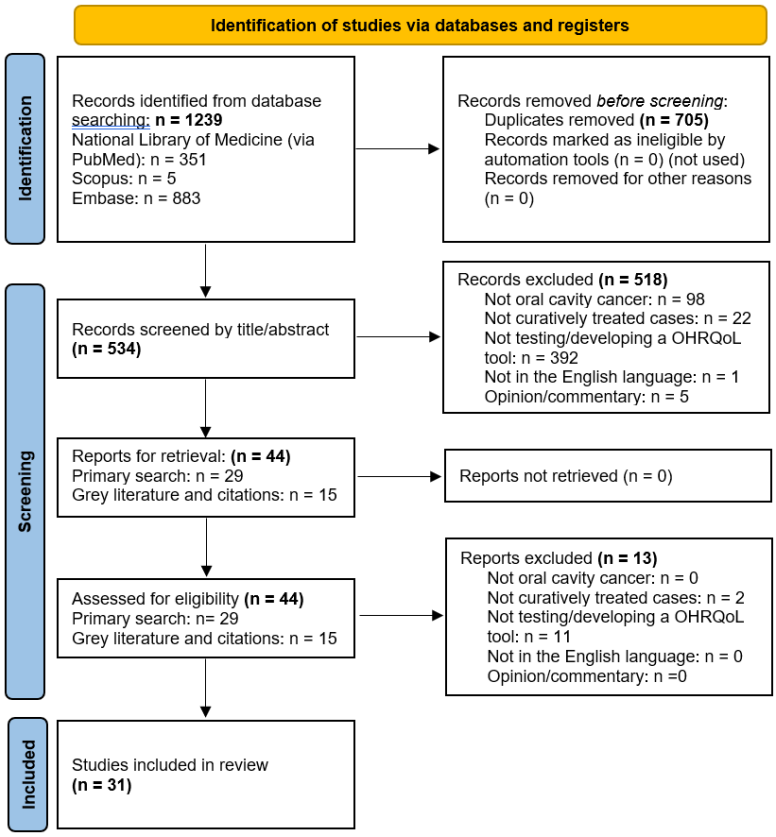

Figure 1 - A PRISMA flowchart of the article selection process.

Summary of articles

A total of 31 articles were included in this review. A range of articles were identified:

1. Four review studies
    a. Systematic review of QoL outcomes following fibula flap [15]
    b. Systematic review studies reporting on the EORTC QLQ-H&N35[16]
    c. Scoping review of the validity/reliability of tools measuring oral function after radiotherapy[5]
    d. A systematic review of humanistic outcomes in oral cancer patients[13]
2. Two cohort studies testing QoL tools (total patients = 200) [17,18]
3. Twenty-four cross-sectional studies translating or testing QoL tools (total patients = 4463) [6,14,27–36,19,37–40,20–26]
4. One publication reported on multiple individual studies developing and testing the QLQ-OH17 (total patients = 151) [41]

Table 2 summarizes studies, Table 3 outlines tool validation and reliability tests, and Table 4 details the items and domains addressed by the tools.

Study number	Type	Study author	Year	Country	Title	Aim	Sample size	Population (cancer types)	Tools
2	Peer review publication	Stanisic, Dekovic, Kozomara, Mladenovic, Mijailovic, Djurdjevic, Jovanovic, Vujovic	2024	Serbia	Translation, transcultural adaptation, and validation of the serbian version of the University of Washington Quality of Life study questionnaire (UW-QoL) – a pilot study	Translate, culturally adapt, and assess the psychometric properties of UW-QoL to Serbian	30	HNC - Radiotherapy treatment	OHIP-14, ERQ
6	Peer review publication	Vermaire, Raaijmakers, Verdonck-de Leeuw, Janssen, Leemans, Terhaard, Speksnijder	2021	Netherlands	Mastication, swallowing, and salivary flow in patients with head and neck cancer: objective tests versus patient-reported outcomes	Assess association between objective tests and patient reported outcomes	142	HNC	QLQ-H&N35, SWAL-QoL-NL, GRIX
7	Peer review publication	Qamar, Rizi, Sawani, Awan, Akhter, Siddiqui, Abbas, Talmooi, Khan	2024	Pakistan	Oral health related quality of life in head and neck cancer survivors within the first year following treatment: a cross-sectional study in Karachi, Pakistan	Assess OHRQoL and its associated with SES, OH practice, OH status, oral mucositis grade	79	HNC	QLQ-H&N35
10	Conference abstract	Anuru, Vadlamudi	2016	India	Evaluating humanistic outcomes for oral cancer patients in india: a systematic literature	Review the scientific literature for last 15 years measuring humanistic outcomes of Oral Cancer survivors in India	43 studies	Oral cancer	AWAITING INFORMATION FIRST AUTHOR CONTACTED 05072024
12	Peer review publication	Hjermstad, Bergenmar, Bjordal, Fløtner, Hofmeister, Montel, Nicolatou-Galitis, Pinto, Raber-Durlacher, Singer, Tomaszewska, Tomaszewski, Leeuw, Yerom, Winterberg, Herlofson, EORTC QoL Group	2016	Norway	International field testing of the psychometric properties of an EORTC quality of life module for oral health: the EORTC QLQ-OH15	Phase IV study testing the psychometric properties of QLQ-OH15	72	HNC	QLQ-C30, QLQ-OH15
13	Conference abstract	Kolnick, Deng, Epstein, Miglioratti, Redi, Dietrich, Murphy	2013	USA	Validation of late oral health outcomes, an oral health subscale of the Vanderbilt Head and Neck Symptom Survey in post-radiation therapy head and neck cancer patients	Validation of the oral health subscale of the VHNSS 2.0	50	HNC - Chemoradiotherapy treatment	VHNSS 2.0
15	Peer review publication	Ridner, Rhoten, Niermann, Murphy, Dietrick	2018	USA	Vanderbilt head and neck symptom survey, version 2.0: Clinical and research utility for identification of symptom clusters and changes in symptoms over time	Identify symptoms clusters, and assess reliability and sensitivity of the VHNSS 2.0 to change	150	HNC - Some data sources included radiotherapy treatment only	VHNSS 2.0
16	Peer review publication	Veld, Jager, Chhangur, Zeeemer, Leusink, Schulten	2023	Netherlands	Oral-Functioning Questionnaires in Patients with Head and Neck Cancer: A Scoping Review	Map the available questionnaires for radiotherapy treated HNC patients	N/A	HNC - Radiotherapy treatment	FACT H&N, UW-QoL, UW-QoL RTOG, QLQ-C30, QLQ-H&N35, QLQ-H&N43, QLQ-OH15, QLQ-OH17, VHNSS 1.0, VHNSS 2.0, EQ-5D-3L, QOL-APC, QOL-RTI-H&N, LORQ, OHIP-14, PI20
18	Peer review publication	Kosgallana, Fayasekara, Abeysinghe, Hjermstad, Lalloo	2022	Sri Lanka	Translation and validation of Sinhala version of modified EORTC QLQ-OH15 in oral cancer patients who receive radiotherapy with or without chemotherapy in Sri Lanka	Translate and validate QLQ-OH15 to Sinhala	85	Oral cancer - Radiotherapy treatment	QLQ-C30, QLQ-OH15
19	Peer review publication	Petrovic, Paschal, Francis, Hernandez, McCarthy, Shah	2019	USA	A Systematic review of validated tools assessing functional and aesthetic outcomes following fibula free flap reconstruction of the mandible	Evaluate the assessment of patient reported outcomes in the literature	N/A	HNC - Segmental mandibulectomy and FFF	UWQoL, OHIP-14, OHIP-49, QLQ-H&N35, MOS SF-36
20	Peer review publication	Hagio, Ishizaki, Ryu, Nomura, Takano, Sakurai	2018	Japan	Maxillofacial prosthetic treatment factors affecting oral health-related quality of life after surgery for patients with oral cancer	Assess the factors influencing OHIP-I54 scores before and after provision of prostheses	50	Oral cancer - Surgical treatment	OHIP-I49
21	Peer review publication	Engelen, Buurman, Bronkhorst, Heuman	2018	Netherlands	Translation, cross-cultural adaptation, and validation of the Liverpool Oral Rehabilitation Questionnaire (LORQ) into the Dutch language	Translation and validation of LORQ 3.0	158	Unclear - patients presenting to the department for dentures	LORQ 3.0, OHIP-NL14
24	Peer review publication	Barroso, Carvalho, Paiva, Murphy, Paiva	2015	Brazil	The Vanderbilt Head and Neck Symptom Survey Brazilian Portuguese version 2.0 (VHNSS 2.0): psychometric properties for patients with head and neck cancer who have undergone radiotherapy	Evaluate the psychometric properties of VHNSS 2.0	241	HNC - Radiotherapy treatment	QLQ-C30, QLQ-H&N35, VHNSS 2.0
25	Peer review publication	Kolnick, Deng, Epstein, Miglioratti, Redi, Dietrich, Murphy	2014	USA	Associations of oral health items of the Vanderbilt Head and Neck Symptom Survey with a dental health assessment	Association between OHRQoL findings and clinical findings	50	HNC - Chemoradiotherapy treatment	VHNSS 2.0
27	Peer review publication	Hjermstad, Bergenmar, Bjordal, Fløtner, Montel, Nicolatou-Galitis, Raber-Durlacher, Singer, Leeuw, Wels, Yerom, Herlofson	2012	Norway	The EORTC QLQ-OH17: A supplementary module to the EORTC QLQ-C30 for assessment of oral health and quality of life in cancer patients	To develop an OHRQoL tool	18, 133	Varied	QLQ-OH17
28	Peer review publication	Pace-Balzan, Butterworth, Dawson, Lowe, Rogers	2006	UK	The further development and validation of the Liverpool Oral Rehabilitation Questionnaire (LORQ) version 3: A cross-sectional survey of patients referred to a dental hospital for removable prostheses replacement	To develop an OHRQoL tool	154	Unclear - patients presenting to the department from primary care	LORQ 3.0, OHIP-14
29	Peer review publication	Sherman, Simonton, Adams, Vural, Owens, Hanna	2000	USA	Assessing Quality of Life in Patients With Head and Neck Cancer	Cross-validation of the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Head and Neck Module (QLQ-H&N35)	120 (30 HNC)	HNC and comparison non-malignant population	QLQ-C30, QLQ-H&N35
31	Peer review publication	Zahid, Martins, Zahid, Asim, Ikram, Hassan, Bhamani, Jabbar, Asad, Akhtar, Siddiqui, Awan, Ahmad	2022	Pakistan	Psychometric properties of the Urdu version of the EORTC QLQ-H&N35 (European organization for research and treatment of cancer head and neck module) quality of life tool	Translate, and validate the EORTC H&N35 to Urdu	250	HNC - Primary oral (82%)	QLQ-C30, QLQ-H&N35, RS-14, HADS
32	Peer review publication	Murphy, Dietrich, Wells, Dwyer, Ridner, Silver, Gilbert, Chung, Cmelak, Burkey, Yarbrough, Sinard, Netterville	2009	USA	Reliability and validity of the vanderbilt head and neck symptom survey: a tool to assess symptom burden in patients treated with chemoradiatio	Validation of the VHNSS 1.0	332	HNC - Chemoradiotherapy treatment	VHNSS 1.0
33	Peer review publication	Cooperstein, Gilbert, Epstein, Dietrich, Bond, Ridner, Wells, Cmelak, Murphy	2012	USA	Vanderbilt head and neck symptom survey version 2.0: report of the development and initial testing of a subscale for assessment of oral health	Development of the OHRQoL tool	70	HNC - Radiotherapy treatment	VHNSS 2.0
34	Peer review publication	Jayasekara, Rajapaksa, Aernsson	2009	Sri Lanka	Health-related quality-of-life in patients with H&N cancer in Sri Lanka: psychometric properties of the 'Sinhala' version of the EORTC QLQ-H&N3	Translate QLQ-H&N35	196	HNC	QLQ-C30, QLQ-H&N35
35	Peer review publication	Yekaninejad, Pakpour, Tadakamadla, Kumar, Mosavi, Fridlund, Bottomley, Aaronson	2015	Iran	Oral-health-related quality of life in patients with cancer: cultural adaptation and the psychometric testing of the Persian version of EORTC QLQ-OH17	To validate the Persian version of the QLQ-OH17	729	HNC	QLQ-C30, QLQ-OH17
36	Peer review publication	Liu, Gao, Wu, Bai, Li, Guo, Yu, Xiao, Bao, He, Zhang, Chen	2018	China	Reliability, validity and responsiveness of the Mandarin (Simplified) Chinese version of the EORTC QLQ-OH45 among cancer patients	Translate, and validate the Mandarin version of QLQ-OH45	393	HNC	QLQ-C30, QLQ-OH15
37	Peer review publication	Bjordal, Hammerlid, Elmquist, Graeff, Boysen, Evensen, Biörklund, Leeuw, Fayers, Jannert, Weeltin, Kaasa, EORTC QoL Group	1999	Norway	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	Develop and validate QLQ-H&N35	500	HNC	QLQ-C30, QLQ-H&N35
38	Peer review publication	Bjordal, Graeff, Fayers, Hammerlid, Pottelsberghe, Curran, Elmquist, Maher, Mayze, Bredart, Sodeholm, Arraras, Palmi, Abendstein, Morton, Pignon, Huguenin, Bottomley, Kaasa, EORTC QoL Group	2000	Norway	A 12-country field study of the EORTC QLQ-C30 (version 3.0) and the head and neck cancer specific module (EORTC QLQ-H&N35) in head and neck patients	Test the validity and reliability of the QLQ-H&N35	622	HNC	QLQ-C30, QLQ-H&N35
39	Peer review publication	Singer, Arraras, Chiesi, Fisher, Galatas, Hammerlid, Galdis, Schmalz, Leeuw, Gamper, Kaasche, Hofmeister	2013	Germany	Performance of the EORTC questionnaire for the assessment of quality of life in head and neck cancer patients EORTC QLQ-H&N35: a methodological review	Assess the language availability, psychometric properties, and acceptance of the QLQ-H&N35	136 papers	HNC - various	QLQ-C30, QLQ-H&N35
40	Peer review publication	Barroso, Carvalho, Paiva, Nunes, Paiva	2014	Brazil	Translation and cross-cultural adaptation into Brazilian Portuguese of the Vanderbilt Head and Neck Symptom Survey version 2.0 (VHNSS 2.0) for the assessment of oral symptoms in head and neck cancer patients submitted to radiotherapy	Translate and validate the Portugese version of the VHNSS 2.0	37	HNC	VHNSS 2.0
42	Peer review publication	Pace-Balzan, Cawood, Howell, Lowe, Rogers	2004	UK	The Liverpool Oral Rehabilitation Questionnaire: a pilot study	Pilot questionnaire	61	Attendance at oral rehabilitation clinic	LORQ, QLQ-H&N35
43	Peer review publication	Kornblith, Zlotolow, Goosen, Hunyh, Lerner, Strong, Shush, Spiro, Holland	1996	USA	Quality of life of maxillectomy patients using an obturator prosthesis	Unclear: the article tests the OPS and its association with patient recovery, psychological adjustment to illness scale, and marital health inventory	47	HNC - Obturator	OPS
44	Peer review publication	Karatas, Balik, Evliioglu, Uysal, Peker	2018	Turkey	Predictors of obturator functioning and satisfaction in Turkish patients using an obturator prosthesis after maxillectomy	Translate and test sensitivity of OPS	41	HNC - Obturator	OPS
45	Peer review publication	Cleary, Guerin, Fagan, Davies	2023	Ireland	The Oral Symptom Assessment Scale (OSAS): criterion validation with the EORTC QLQ-OH15 and reliability testing	Test criterion validity and reliability	54	Advanced cancer/palliative	OSAS QLQ-OH15

Table 2 – Summary of the articles accepted into the scoping review

Identified QoL tools

We identified a range of tools being used to assess patient-reported outcomes in HNC. The tools identified can be characterised as:

1. General population tools (GT), cancer-specific tools (CT), or HNC-specific tools (HNT)
2. Health related QoL (HRQoL) tool, OHRQoL tool, or patient (symptom) survey

Information related to the development methodology, testing, availability, and readability of tools is summarized in tables 2-4. We have not performed a quality analysis of studies. Thus, caution should be exercised when interpreting findings; they merely represent an attempt to perform a type of testing/development, rather than the quality of said methods.

Nineteen tools were identified. These include the EORTC core (QLQ-C30), head and neck (QLQ-H&N35 and QLQ-H&N43), and oral health tools (QLQ-OH15 and QLQ-OH17); OHIP tools (14 and 49); LORQ v1.0-3.0,

VHNSS 1.0-2.0, OFS, OSAS, FACE-Q, FACT H&N, UWQoL, EQ-5D-5L v4, and MOS SF-36. The LORQ and VHNSS represent patient surveys to assess oral rehabilitation and patient symptoms, whilst the remainder of the tools represent either HRQoL or OHRQoL tools. In addition, the EORTC tools are designed for use in combination with one another (core item list with additional modules). The tools identified alongside the existence of studies to achieve concurrent validity between questionnaires are summarised in Figure 2.

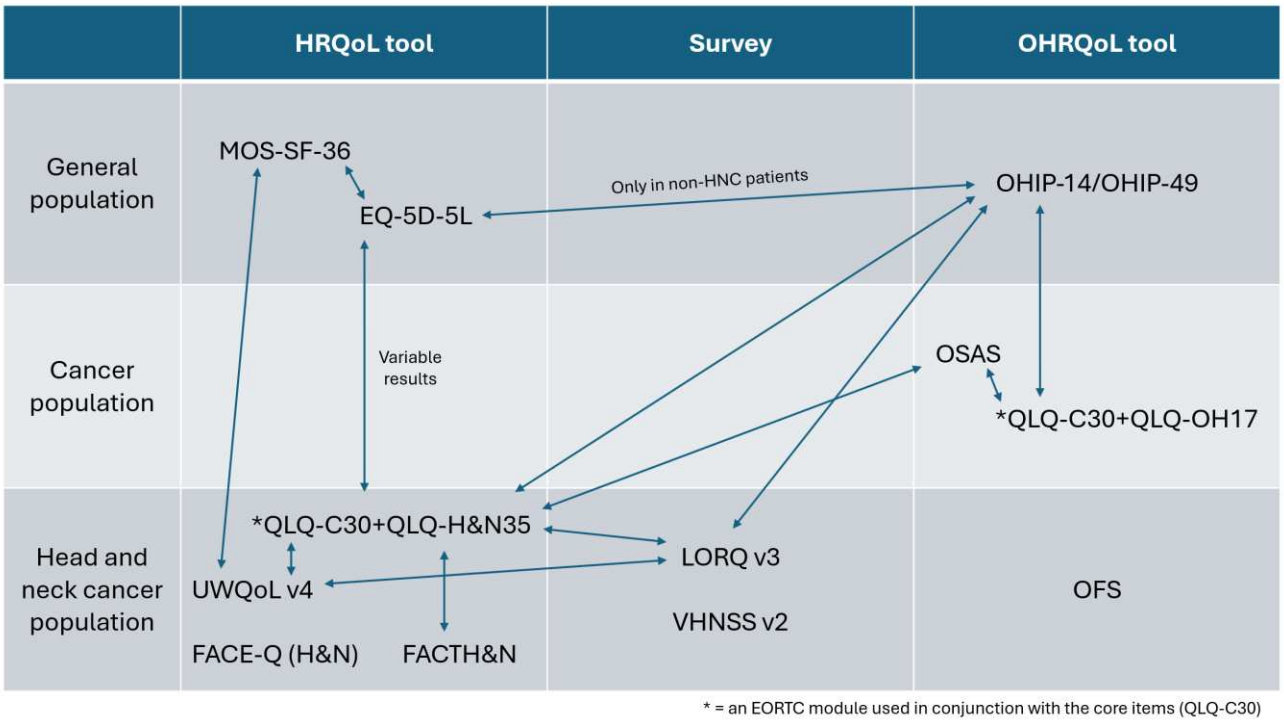

Figure 2 - The tools identified are grouped based on the tool type and population they have been designed for. Arrows indicate the presence of published peer-reviewed studies reporting on the concurrent validity between questionnaires. OSAS is designed for the advanced and palliative care cancer population only.

Characteristics of the identified tools

Method of tool construction

The tool development method influences the likelihood of a tool being complete, appropriate, acceptable and usable. Stakeholders such as the target population and treating clinicians should be included at multiple stages of research and should form the theoretical grounding for the items in a tool.[42] The development methods for questionnaires varied but were often poorly described.

EORTC and OHIP were the only tools that adhered to recommendations regarding stakeholder involvement. This involvement extended beyond patient interviewing, for example, with the use of respondent validation. Other methods used to develop QoL tools included professional opinion, expert consensus, focus groups, symptom/experience surveys, topic prioritization cards, and literature reviews (see Table 2).

The EORTC modules, VHNSS, LORQ, UWQoL, and EQ series tools all underwent four distinct phases of tool development and have been revised through multiple published iterations. EORTC is the only HNT that has undergone all four recommended phases of tool development.[42] The EORTC group were the only group to reference published standards for QoL tool development.[43]

Completeness (domains and items)

The domains of OHRQoL are oral function, orofacial pain, appearance, and psychosocial impact. Treatment expectation is also sometimes included. There is no independent and objective measure of the completeness of an OHRQoL tool, as this will fundamentally be scenario-dependent. We developed a completeness matrix by combining accepted OHRQoL items with HNC-specific oral health items identified from included studies (see Table 4). In this process, all 600 items from the identified QoL tools were collated, de-duplicated and grouped into clusters relating to health impacts, thus forming 19 potentially relevant oral health impacts. None of the tools measured all potentially relevant items. Oral health and function domains were the most assessed, whilst treatment expectation and satisfaction were the least assessed domains. HRQoL tools more commonly assessed environment impacts, whereas OHRQoL tools focussed on social/emotional domains. Self-perceived dental health was assessed by the EORTC H&N and OH modules, the OHIP tools, OSAS, and VHNSS 2.0. Spacing between teeth was only assessed by the OHIP tools.

A failure of tools to measure all potential items does not indicate with certainty that they are incomplete, but rather that there is ambiguity in this regard. This can be further investigated through the use of mixed-methods studies to determine the oral health impacts that are the most relevant and important in the representation of the patient experience.

Validity and reliability

None of the tools identified had undergone comprehensive assessment of validity and reliability as recommended by COSMIN (Table 3). Whilst content validity testing was performed for most tools, this was often not repeated when tools were translated or adapted for use in other cultures. Assessment of content validity should involve patient/clinician stakeholders who can input on acceptability, comprehensiveness, relevance of items, clarity of wording and ambiguity of items[42]; this was only performed in the HNC cohort for the EORTC tools.

The target population varied between tools. Consequently, the validation of some tools was limited to specific populations, resulting in case-specific validity. The OFS is inherently limited to cases of maxillectomy restored with an obturator. The OSAS was developed and tested for all advanced cancers; it was unclear whether validation in curative oral cavity cancer cases was performed. The VHNSS tools were developed for cases treated with radiotherapy. The EQ-5D-5L is a generic tool, however several studies reported failure to achieve construct validity as well as a lack of sensitivity in HNC cases.

Most studies focussed on evaluating criterion validity, construct validity, test-retest reliability, and internal consistency. Split-half reliability was performed for one tool group (OHIP). None of the tools have sufficient validity and reliability testing to meet the COSMIN criteria.[44–46]

Availability

All tools were available online alongside licensing information, which enabled free use for non-commercial purposes, including academic research. Modification of tools is not permitted.

Language translations and cultural adaptation were available for most tools; however, content validity was rarely re-evaluated in this context. Many tools were constructed in Western developed countries with subsequent translation and cultural adaptation. Cultural acceptability, administrative burden, and language bias were not reported for any of the tools.

Readability

The Flesch-Kincaid readability score of tools ranged from 1.2 to 6.7. A score below eight is recommended for public documentations in developed countries.[47]

The readability score and burden of a questionnaire are influenced by its design. The number of items used in tools varied between 5 (EQ series) and 102 (FACE-Q). All tools utilised a horizontal scale to determine the strength of a measure. This varied from a 3-point problem-based verbal rating scale to a 10-point Likert scale. Some tools also employed dichotomous answering systems.

Type	Tool	QoL or OHRQoL	Generic or OH specific	Methods of tool construction	Key stakeholders involved	Stakeholder role	Saturation reached	Year of tool development	Comparison against (tool)	Criterion validity	Content validity	Construct validity	Clinical validity	Test-retest reliability	Internal consistency	Split-half reliability	Responsiveness	Validated for HNC	Language validated	Cultural adaptation	Interpretability	Administrative burden	FK Grade	FK Reading Ease
OHRQoL	OFS	HNC	OH specific	Expert consensus	Unknown	Unknown	Unknown	1996	Nil	No	No	Yes	No	No	No	No	Yes	Maxillectomy patients only	Multiple	Multiple	Unknown	Unknown	6.5	57.6
OHRQoL	QLQ-OH15	HNC	OH specific	Literature review, professional interviews and patient interviews	Specialist clinicians, patients	Involvement in all phases of questionnaire constructions	Yes	2016	OSAS, OHIP-14, OHIP-49	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Multiple	Multiple	Yes	Unknown	3.2	82.6
OHRQoL	QLQ-OH17	HNC	OH specific	Literature review, professional interviews and patient interviews	Specialist clinicians, patients	Involvement in all phases of questionnaire constructions	Yes	2012	OSAS, OHIP-14, OHIP-49	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Multiple	Multiple	Yes	Unknown	3.6	76
OHRQoL	OHIP-14	GT	OH specific	Population interviews, paired comparisons	Individuals (general population)	Interviews, post-publication readability and interpretability	Yes	1997	OHIP-49, OHIP-Edent, QLQ-C30+QLQ-OHN35, LORQ, EQ-5D-5L	Yes	Yes - non-oral cancer population	Yes	Yes	Yes	Yes	Yes	Yes - non-oral cancer population	Yes	Multiple	Multiple	Yes	Unknown	6.2	74.7
OHRQoL	OHIP-49	GT	OH specific	Population interviews, paired comparisons	Individuals (general population)	Interviews, post-publication readability and interpretability	Yes	1994	OHIP-14, OHIP-Edent, QLQ-C30+QLQ-OHN35, LORQ, EQ-5D-5L	Yes	Yes - non-oral cancer population	Yes	Yes	Yes	Yes	Yes	Yes - non-oral cancer population	Yes	Multiple	Multiple	Yes	Unknown	6.2	74.7
OHRQoL	OSAS	Advanced palliative cancers	OH specific	Literature review and expert opinion	Specialist clinicians	Feedback on wording	N/A	2021	QLQ-OH15	Yes	Yes	No	No	Yes	No	No	No	Palliative care only	Nil	Nil	Unknown	Unknown	6.7	51.7
Oral concerns inventory	LORQ v1	HNC	OH specific	Expert consensus	Unknown	Unknown	No	2004	Unclear	No	Yes	No	Yes	Yes	Yes	No	No	Yes	Nil	Nil	Unknown	Unknown	5.8	70.4
Oral concerns inventory	LORQ v2	HNC	OH specific	Expert consensus	Unknown	Unknown	No		Unclear	Unclear								Yes	Nil	Nil	Unknown	Unknown		
Oral concerns inventory	LORQ v3	HNC	OH specific	Expert consensus	Unknown	Unknown	Unknown	2006	OHIP-14, UWQoL, QLQ-H&N35	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Multiple	Multiple	Unknown	Unknown	3.7	75.8
Oral concerns inventory	VHNSS 2.0	HNC	OH specific	Literature review, expert consensus including physicians, dentists and patients	Specialist clinicians, patients	Involvement in all phases of questionnaire constructions	No	2011	Nil	Yes	Yes	Yes	No	No	Yes	No	Yes	Radiotherapy cases only	Multiple	Multiple	Unknown	Unknown	2.9	83.3
Oral concerns inventory	VHNSS 1.0	HNC	Generic	Symptom survey	Specialist clinicians	Symptom survey	No	2009	Nil	Yes	Yes	Yes	No	No	Yes	No	Yes	Radiotherapy cases only	Nil	Nil	Unknown	Unknown	2.9	83.5
QoL	FACE-Q	HNC	Generic	Qualitative interviews, literature review, expert opinion	Clinicians	Semi-structured interviews	Unknown	2016	Nil		Yes	Yes	Yes	Yes	Yes			Yes	Multiple	Multiple	Unknown	Unknown	1.2	93.1
QoL	FACT-H&N	HNC	Generic	Interviews, professional opinion	Specialist clinicians, patients	Unknown	Unknown	1996	MDADI, QLQ-C30, QLQ-H&N35	No	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Multiple	Multiple	Unknown	Unknown	1.8	91.6
QoL	QLQ-C30	HNC	Generic	Literature review, professional interviews and patient interviews	Specialist clinicians, patients	Involvement in all phases of questionnaire constructions	Yes	1993	OSAS, OHIP-14, OHIP-49, LORQ, EQ-5D-5L (in conjunction with EORTC H&N tool).	No		Yes						Yes	Multiple	Multiple	Yes	Unknown	4.1	74.8
QoL	QLQ-H&N35	HNC	Generic	Literature review, professional interviews and patient interviews	Specialist clinicians, patients	Involvement in all phases of questionnaire constructions	Yes	1999	OSAS, OHIP-14, OHIP-49, LORQ, EQ-5D-5L	Yes		Yes		Yes	Yes		Yes	Yes	Multiple	Multiple	Yes	Unknown	1.4	92.6
QoL	QLQ-H&N43	HNC	Generic	Literature review, professional interviews and patient interviews	Specialist clinicians, patients	Involvement in all phases of questionnaire constructions	Yes	2014	OSAS, OHIP-14, OHIP-49, LORQ, EQ-5D-5L	Yes		Yes		Yes	Yes		Yes	Yes	Multiple	Multiple	Yes	Unknown	1.5	92.2
QoL	UW-QoL	HNC	Generic	Literature review, professional interviews and patient interviews	Specialist clinicians, patients	Unknown	Yes	1999	LORQ, QLQ-C30, HOS SF-36	No	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Multiple	Multiple	Yes	Unknown	5.4	71.6
QoL	EQ-5D-5L v4	GT	Generic	Stakeholder focus groups	Individuals (general population)	Unknown	Yes	2011	UW-QoL, QLQ-C30, QLQ-HN35, OHIP in non-HNC populations only	No	No	No	No	Yes	Yes	No	No	Construct validity not achieved in studies (Nord 2022), poor sensitivity (Gwee 2019)	Multiple	Multiple	Yes	Unknown	7	56.3
QoL	HOS SF-36	GT	Generic	Literature review, professional opinion	Unknown	Unknown	Unknown	1992	EQ-5D-5L, UW-QoL	No	No	No	No	No	No	No	No	No	Multiple	Multiple	Yes	Unknown	4.1	74.9

Table 3 - a summary of the types of QoL identified alongside the method of construction and testing methods reported in the published literature for each tool.

						Oral health							Function							Treatment expectation	Environment	Social and emotional		
Type	Tool	OT or HNC	Generic or OH specific or other	Number of items	Outcome scale used	Pain	Dental health	Bleeding gums	Sores/ulcers	Thick/stiffened saliva	Dry mouth	Spaces between teeth	Chewing	Choke/gag/swallow/nodding stuck	Eating (general)	Talking	Taste	Mouth opening	Dentures	Treatment satisfaction	School/job/public environments	Anxiety	Attractive/ Appearance	Unhappy
OHRQoL	OFS	HNC	OH specific	13	5-point Likert						Yes		Yes	Yes		Yes					Yes		Yes	
OHRQoL	QLQ-OH15	HNC	OH specific	15	4-point Likert	Yes	Yes	Yes	Yes	Yes	Yes		H&N35/43	H&N35/43	Yes	H&N35/43	Yes	H&N35/43	Yes	H&N35/43	H&N35/43	H&N35/43	H&N35/43	H&N35/43
OHRQoL	QLQ-OH17	HNC	OH specific	17	4-point Likert and Dichotomous (Yes/No)	Yes	Yes	Yes	Yes	Yes	Yes		H&N35/43	H&N35/43	Yes	H&N35/43	Yes	H&N35/43	Yes	Partial = H&N35/43	H&N35/43	H&N35/43	H&N35/43	H&N35/43
OHRQoL	OHIP-14	GT	OH specific	14	5-point Likert	Yes		Yes				Yes	Yes			Yes				Yes	Yes	Yes	Yes	Yes
OHRQoL	OHIP-49	GT	OH specific	49	5-point Likert	Yes		Yes				Yes	Yes			Yes				Yes	Yes	Yes	Yes	Yes
OHRQoL	OSAS	Advanced/palliative cancers	OH specific	20	4-point and 5-point Likert	Yes	Yes		Yes		Yes		Yes	Yes		Yes	Yes		Yes					
Oral concerns inventory	LORQ v1	HNC	OH specific	25	4-point Likert						Yes		Yes	Yes	Yes	Yes			Yes		Yes	Yes	Yes	Yes
Oral concerns inventory	LORQ v2	HNC	OH specific	25	4-point Likert																			
Oral concerns inventory	LORQ v3	HNC	OH specific	40	4-point Likert	Partial		Yes			Yes		Yes	Yes		Yes			Yes				Yes	Yes
Oral concerns inventory	VHNSS 2.0	HNC	OH specific	56	10-point Likert	Yes	Yes		Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes					
Oral concerns inventory	VHNSS 1.0	HNC	Generic	28	10-point Likert	Yes			Yes	Yes	Yes			Yes	Yes	Yes	Yes							
QoL	FACE-Q	HNC	Generic	102	3-point and 4-point Likert						Yes		Yes	Yes	Yes	Yes	Yes	Yes			Yes	Yes	Yes	Yes
QoL	QLQ-H&N35	HNC	Generic	35	4-point Likert	Yes	Yes		Yes	Yes	Yes		Yes	Yes	Yes	Partial	Yes	Yes		Yes	Yes	Yes	Yes	Yes
QoL	QLQ-H&N43	HNC	Generic	43	4-point Likert	Yes	Yes		Yes	Yes	Yes		Yes	Yes	Yes	Partial	Yes	Yes		Yes	Yes	Yes	Yes	Yes
QoL	UW-QoL	HNC	Generic	12	3-6-point Likert	Yes					Yes		Yes	Yes	Yes	Yes	Yes					Yes	Yes	
QoL	EQ-5D-5L v4	GT	Generic	5	3-point problem based verbal rating scale	Yes																Yes		
QoL	FACT-H&N	HNC	Generic	39	5-point Likert	Yes					Yes			Yes	Yes	Yes					Yes	Yes	Yes	Yes
QoL	MOS SF-36	GT	Generic	36	3-6-point Likert and Dichotomous (Yes/No)																Yes	Yes		Yes
QoL	QLQ-C30	GT	Generic	30	4-point and 7-point Likert	Yes															Yes	Yes		

Table 4 - a summary of the potential domains of OHRQoL in the HNC population that are measured by each tool. This table does not provide an indication of the quality of the tool and its ability to measure each item or domain effectively.

Discussion

We identified numerous studies reporting on PROs, including patient symptom survey and QoL tools. Some studies did not distinguish between these two types of tools.[5,6,24] Whilst several different tools have been identified, most of these were not designed to measure *OHRQoL* in *HNC*. Figure 2 shows that one tool was designed for this purpose but is limited to maxillectomy/obturator cases. Evidence to support the completeness and salience of tools to measure OHRQoL in HNC was lacking. Further research is required to explore the suitability of existing tools in measuring OHRQoL in the HNC population.

Various tool development methodologies have been used, with limited reference to gold standards. Consequently, there is a risk these tools do not accurately and reliably measure OHRQoL in this cohort. This is particularly evident where studies report a lack of responsiveness and sensitivity, or ceiling. The development of a QoL tool should involve four distinct phases[42]. Only one HNC-specific HRQoL tool and one cancer-specific OHRQoL tool involved these phases: QLQ-H&N and QLQ-OH series respectively. No HNC-specific OHRQoL tool involved all phases. These limitations increase the likelihood of tools being missing key impacts of OHRQoL relevant to HNC patients and thus lacking content validity.[42] In addition, some tools may not be completely adapted for use in other languages and cultures. For example, in one study a tool was translated and deemed to have achieved construct validity and acceptance by a study population despite 36.5% of the study participants requiring assistance in completing the questionnaire.[23,42]

Several published standards exist to assess the measurement properties of QoL tools.[48] None of the identified studies referenced independently published standards. Most tools underwent some testing for validity and reliability, however none have undergone comprehensive testing. Additionally, some tools were developed/tested over 10 years ago. Given the significant changes in the epidemiology and treatment of HNCs since then, the maintenance of validity of these tools is uncertain. Whilst these tools may retain validity, this has not been investigated with contemporary research, including modern treatment and rehabilitation techniques, or the contemporary HNC population.

The literature search identified a range of tools, including those designed specifically for HNC patients and others intended for broader cancer cohorts. Most HNTs focused on measuring functional impacts like eating, speaking, and swallowing, and often overlooked the domains of treatment expectation, environment, and social/emotional well-being. These additional domains are crucial for gaining a more comprehensive understanding of QoL and are well-recognized as important aspects of OHRQoL.[49]

The items assessed by different tools vary, further suggesting that they are missing key items. Impacts related to the dentition (such as dental appearance, function, and dental pain) were frequently missing, particularly from HRQoL tools. This contrasts with the literature indicating that dental concerns are common in the HNC population.[50] Some of the identified tools measured all domains of OHRQoL, but they failed to measure specific items that are likely important to HNC patients. One GT tool (OHIP-14), for example, provides a holistic measurement of OHRQoL for the general population, encompassing all accepted domains of OHRQoL. However, it doesn't assess dry mouth, altered salivary consistency, difficulty opening the mouth, and altered facial appearance, and may therefore fail to achieve this same level of holistic measurement in the HNC population.

It is proposed that incomplete questionnaires can achieve criterion and construct validity if the qualitative grounding for questionnaire construction is flawed or missing.[42] Some of these missing factors may have little impact on overall health experiences, or other, more general questions may capture their impact. For example, while questions related to dry mouth are missing from OHIP-14, the oral health impacts of dry mouth may be captured by questions such as: "Have you had to interrupt meals because of problems with your teeth, mouth or dentures?". Consequently, it is unclear whether the available QoL tools capture the *salience* of the oral health experience of HNC through the range of items they assess. Thus, further research should aim to resolve ambiguity regarding the relevant oral health impacts in contemporary HNC patients, using the existing QoL tools as a reference.

One qualitative research study (with preliminary findings) indicates that multiple potential oral health impacts are not assessed by the identified QoL tools.[51] Despite this, the importance of the reported impacts on the overall OHRQoL experience of HNC patients is unknown. Consequently, the importance of these impacts on the validity of QoL tools is uncertain. It is important that a questionnaire doesn't aim to assess all oral health impacts. The purpose of a QoL tool is to assess the health impacts that are of greatest relevance and importance to provide an overarching score that is representative of the patient experience. Consequently, QoL should undergo a phase of item list refinement. A QoL tool that is excessively long is less likely to be completed accurately, and may not be completed at all due to the burden associated with this. Despite this, there is potential for excessively short questionnaires to miss important health impacts. Item list refinement is often completed using a number of methods including stakeholder consensus, and evaluation of the psychometric properties of the QoL tool.

A OHRQoL questionnaire must be able to evidence precision and responsiveness. The feasibility of this depends on the definition (and acceptance) of a minimum important clinical difference within the HNC population. To facilitate this process, the development of QoL tools must include normative data for comparison in relation to outcomes. However, there is no consensus on what "normative" relates to in the context of the HNC population.

The impact of missing QoL domains differs significantly from that of missing items. The omission a domain may result in a tool which fails to holistically assess QoL. Only the OHIP and EORTC H&N questionnaires measure all domains of OHRQoL. All other identified questionnaires, including the EORTC QLQ-C30 in combination with the EORTC QLQ-OH15/17, do not measure all domains of OHRQoL.

The utilisation of a range of methodologies in phases of tool development is recommended.[45,48] This facilitates iterative development/testing of the tool, including the relevance/salience of items, interpretability/readability of questions, and length/structure. Failure to follow this can result in a tool that does not represent key aspects of the patient experience.[42,45] Furthermore, the patient involvement process must be performed with a robust methodology to minimise bias and ensure the sample is representative and of sufficient size. Many of the identified tools were developed without robust stakeholder involvement. Future research should explore the relevance and wording of questionnaire items regarding their appropriateness and relevance.

Conclusion

Our findings suggest that the existing tools have reported most items relevant to OHRQoL in HNC. Despite this, none of these tools comprehensively assess all the potential impacts, and none have undergone comprehensively testing (as per COSMIN criteria). The EORTC OH questionnaires are the only tools designed to assess OHRQoL with testing in HNT. However, they fail to assess all OHRQoL domains. Due to the dearth of evidence, there is no definitive indication that any one tool is optimal for assessing OHRQoL in HNC patients. Consequently, the primary objectives of further research should involve assessing the completeness and appropriateness of tools to measure OHRQoL in the HNC population.

References

[1] Cancer Research UK. Mouth and oral cancer statistics | WCRF International n.d.:2024. https://www.wcrf.org/cancer-trends/mouth-and-oral-cancer-statistics/ (accessed April 3, 2024).

[2] Rogers S. HANDLE Database n.d. https://www.handle-on-qol.com/Index.aspx (accessed March 8, 2024).

[3] Seikaly H, Idris S, Chuka R, Jeffery C, Dzioba A, Makki F, et al. The Alberta Reconstructive Technique: An Occlusion-Driven and Digitally Based Jaw Reconstruction. Laryngoscope 2019;129:S1–14. https://doi.org/10.1002/lary.28064.

[4] Butterworth C, McCaul L, Barclay C. Restorative dentistry and oral rehabilitation: United Kingdom National Multidisciplinary Guidelines. J Laryngol Otol 2016;130:S41–4. https://doi.org/10.1017/S0022215116000414.

[5] In 't Veld M, Jager DHJJ, Chhangur CN, Ziesemer KA, Leusink FKJJ, Schulten EAJMJM, et al. Oral-Functioning Questionnaires in Patients with Head and Neck Cancer: A Scoping Review. J Clin Med 2023;12:3964. https://doi.org/10.3390/jcm12123964.

[6] Pace-Balzan A, Butterworth CJ, Dawson LJ, Lowe D, Rogers SN. The further development and validation of the Liverpool Oral Rehabilitation Questionnaire (LORQ) version 3: A cross-sectional survey of patients referred to a dental hospital for removable prostheses replacement. J Prosthet Dent 2008;99:233–42. https://doi.org/10.1016/S0022-3913(08)60048-7.

[7] Pollock D, Peters MDJ, Khalil H, McInerney P, Alexander L, Tricco AC, et al. Recommendations for the extraction, analysis, and presentation of results in scoping reviews. JBI Evid Synth 2023;21:520–32. https://doi.org/10.11124/JBIES-22-00123.

[8] Patel J, Csikar J, Korfage A, Witjes M, Douglas G, Kanatas A. The oral health experience of oral cancer patients – a scoping review. Open Sci Framew 2024. https://doi.org/10.17605/OSF.IO/G6KES.

[9] Sukhera J. Narrative Reviews: Flexible, Rigorous, and Practical. J Grad Med Educ 2022;14:414–7. https://doi.org/10.4300/JGME-D-22-00480.1.

[10] Peters MDJ, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. JBI Evid Synth 2020;18:2119–26. https://doi.org/10.11124/JBIES-20-00167.

[11] Mourad Ouzzani, Hossam Hammady, Zbys Fedorowicz, Ahmed Elmagarmid. Rayyan — a web and mobile app for systematic reviews. Syst Rev 2016;5:1–10.

[12] Oliffe M, Thompson E, Johnston J, Freeman D, Bagga H, Wong PKK. Assessing the readability and patient comprehension of rheumatology medicine information sheets: A cross-sectional Health Literacy Study. BMJ Open 2019;9. https://doi.org/10.1136/bmjopen-2018-024582.

[13] Aruru MV, Vadlamudi NK. Evaluating Humanistic Outcomes for Oral Cancer Patients in India: a Systematic Literature. Value Heal 2016;19:A95. https://doi.org/10.1016/j.jval.2016.03.1748.

[14] Kolnick, Deng, Epstein, Migliorati, Rezk, Dietrich. Validation of late oral health outcomes, an oral health subscale of the Vanderbilt Head and Neck Symptom Survey in post-radiation therapy head and neck cancer patients. J Clin Oncol 2013;31.

[15] Petrovic I, Panchal H, De Souza Franca PD, Hernandez M, McCarthy CC, Shah JP. A systematic review of validated tools assessing functional and aesthetic outcomes following fibula free flap reconstruction of the mandible. Head Neck 2019;41:248–55. https://doi.org/10.1002/hed.25452.

[16] Singer S, Arraras JI, Chie WC, Fisher SE, Galalae R, Hammerlid E, et al. Performance of the EORTC questionnaire for the assessment of quality of life in head and neck cancer patients EORTC QLQ-H&N35: A methodological review. Qual Life Res 2013;22:1927–41. https://doi.org/10.1007/s11136-012-0325-1.

[17] Ridner SH, Rhoten BA, Niermann KJ, Murphy BA, Dietrich MS. Vanderbilt head and neck symptom survey, version 2.0: Clinical and research utility for identification of symptom clusters and changes in symptoms over time. Oral Oncol 2018;83:25–31. https://doi.org/10.1016/j.oraloncology.2018.05.024.

[18] Hagio M, Ishizaki K, Ryu M, Nomura T, Takano N, Sakurai K. Maxillofacial prosthetic treatment factors affecting oral health-related quality of life after surgery for patients with oral cancer. J Prosthet Dent 2018;119:663–70. https://doi.org/10.1016/j.prosdent.2017.05.017.

[19] Stanišić D, Daković D, Kozomara R, Mladenović R, Mijailović S, Djurdjević M, et al. Translation, transcultural adaptation, and validation of the Serbian version of the University of Washington Quality of Life (UW-QoL) Questionnaire - a pilot study. Vojnosanit Pregl 2024;81:150–61. https://doi.org/10.2298/VSP231020002S.

[20] Vermaire JA, Raaijmakers CPJ, Verdonck-de Leeuw IM, Jansen F, Leemans CR, Terhaard CHJ, et al. Mastication, swallowing and salivary flow in patients with HNC; objective tests versus PROs. Radiother Oncol 2021;161:S842–3. https://doi.org/https://dx.doi.org/10.1016/S0167-8140%2821%2907464-8 PT - Conference Abstract.

[21] Qamar S, Rozi S, Sawani S, Awan MS, Akhtar S, Siddiqui MI, et al. Oral health related quality of life in head and neck cancer survivors within the first year following treatment: a cross-sectional study in Karachi, Pakistan. Sci Rep 2024;14:1–11. https://doi.org/10.1038/s41598-024-52813-x.

[22] Hjermstad MJ, Bergenmar M, Bjordal K, Fisher SE, Hofmeister D, Montel S, et al. International field testing of the psychometric properties of an EORTC quality of life module for oral health: the EORTC QLQ-OH15. Support Care Cancer 2016;24:3915–24. https://doi.org/10.1007/s00520-016-3216-0.

[23] Kosgallana, Jayasekara, Abeysinghe, Hjermstad. Translation and validation of Sinhala version of modified EORTC QLQ-OH15 in oral cancer patients who receive radiotherapy with or without chemotherapy in Sri Lanka. BMC Oral Health 2022;22:359. https://doi.org/https://dx.doi.org/10.1186/s12903-022-02392-y PT - Article.

[24] Engelen M, Buurman DJM, Bronkhorst EM, van Heumen CCM. Translation, cross-cultural adaptation, and validation of the Liverpool Oral Rehabilitation Questionnaire (LORQ) into the Dutch language. J Prosthet Dent 2018;119:239–43. https://doi.org/10.1016/j.prosdent.2017.03.023.

[25] Barroso EM, Carvalho AL, Paiva CE, Murphy BA, Paiva BSR. The Vanderbilt Head and Neck Symptom Survey Brazilian Portuguese version 2.0 (VHNSS 2.0): Psychometric properties for patients with head and neck cancer who have undergone radiotherapy. BMC Res Notes 2015;8:1–11. https://doi.org/10.1186/s13104-015-1470-8.

[26] Kolnick L, Deng J, Epstein JB, Migliorati CA, Rezk J, Dietrich MS, et al. Associations of oral health items of the Vanderbilt Head and Neck Symptom Survey with a dental health assessment. Oral Oncol 2014;50:135–40. https://doi.org/https://dx.doi.org/10.1016/j.oraloncology.2013.10.019 PT - Article.

[27] Sherman AC, Simonton S, Adams DC, Vural E, Owens B, Hanna E. Assessing quality of life in patients with head and neck cancer: Cross- validation of the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life head and neck module (QLQ-H and N35). Arch Otolaryngol - Head Neck Surg 2000;126:459–67. https://doi.org/10.1001/archotol.126.4.459.

[28] Zahid N, Martins RS, Zahid W, Azam I, Ikram M, Hassan A, et al. Psychometric properties of the Urdu version of the EORTC QLQ-H&N35 (European organization for research and treatment of cancer head and neck module) quality of life tool. BMC Psychol 2022;10:1–12. https://doi.org/10.1186/s40359-022-00900-x.

[29] Murphy BA, Dietrich MS, Wells N, Dwyer K, Ridner SH, Silver HJ, 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.

[30] Cooperstein E, Gilbert J, Epstein JB, Dietrich MS, Bond SM, Ridner SH, et al. Vanderbilt head and neck symptom survey version 2.0: Report of the development and initial testing of a subscale for assessment of oral health. Head Neck 2012;34:797–804. https://doi.org/10.1002/hed.21816.

[31] Jayasekara H, Rajapaksa LC, Aaronson NK. Health-related quality-of-life in patients with head-and-neck cancer in Sri Lanka: Psychometric properties of the “Sinhala” version of the EORTC QLQ-H&N35.

Psychooncology 2009;18:1116–21. https://doi.org/10.1002/pon.1430.

[32] Yekaninejad MS, Pakpour AH, Tadakamadla J, Kumar S, Mosavi SH, Fridlund B, et al. Oral-health-related quality of life in patients with cancer: cultural adaptation and the psychometric testing of the Persian version of EORTC QLQ-OH17. Support Care Cancer 2015;23:1215–24. https://doi.org/10.1007/s00520-014-2468-9.

[33] Liu J, Gao J, Wu CX, Bai DX, Li X, Guo XX, et al. Reliability, validity and responsiveness of the Mandarin (Simplified) Chinese version of the EORTC QLQ-OH45 among cancer patients. Eur J Cancer Care (Engl) 2019;28:1–10. https://doi.org/10.1111/ecc.12987.

[34] Bjordal BK, Hammerlid E, Ahlner-elmqvist M, Graeff A De, Boysen M, Evensen JF, 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 1999;17:1008–19.

[35] Bjordal K, De Graeff A, Fayers PM, Hammerlid E, Van Pottelsberghe C, Curran D, et al. A 12 country field study of the EORTC QLQ-C30 (version 3.0) and the head and neck cancer specific module (EORTC QLQ-H and N35) in head and neck patients. Eur J Cancer 2000;36:1796–807. https://doi.org/10.1016/S0959-8049(00)00186-6.

[36] Barroso EM, Carvalho AL, Paiva CE, Nunes JS, Paiva BSR. Translation and cross-cultural adaptation into Brazilian Portuguese of the Vanderbilt Head and Neck Symptom Survey version 2.0 (VHNSS 2.0) for the assessment of oral symptoms in head and neck cancer patients submitted to radiotherapy. Braz J Otorhinolaryngol 2015;81:622–9. https://doi.org/10.1016/j.bjorl.2015.08.014.

[37] Pace-Balzan A, Cawood JI, Howell R, Lowe D, Rogers SN. The Liverpool Oral Rehabilitation Questionnaire: A pilot study. J Oral Rehabil 2004;31:609–17. https://doi.org/10.1111/j.1365-2842.2004.01279.x.

[38] Kornblith AB, Zlotolow IM, Gooen J, Huryn JM, Lerner T, Strong EW, et al. Quality of life of maxillectomy patients using an obturator prosthesis. Head Neck 1996;18:323–34. https://doi.org/10.1002/(sici)1097-0347(199607/08)18:4<323::aid-hed3>3.0.co;2-%23.

[39] Ozdemir-Karatas M, Balik A, Evlioglu G, Uysal Ö, Peker K. Predictors of obturator functioning and satisfaction in Turkish patients using an obturator prosthesis after maxillectomy. Oral Surg Oral Med Oral Pathol Oral Radiol 2018;125:e76–82. https://doi.org/10.1016/j.oooo.2017.11.002.

[40] Cleary N, Guerin S, Fagan N, Davies A. The Oral Symptom Assessment Scale (OSAS): criterion validation with the EORTC QLQ-OH15 and reliability testing. Support Care Cancer 2023;31:1–7. https://doi.org/10.1007/s00520-023-08118-2.

[41] Hjermstad MJ, Bergenmar M, Fisher SE, Montel S, Nicolatou-Galitis O, Raber-Durlacher J, et al. The

436 EORTC QLQ-OH17: A supplementary module to the EORTC QLQ-C30 for assessment of oral health
437 and quality of life in cancer patients. Eur J Cancer 2012;48:2203–11.
438 https://doi.org/10.1016/j.ejca.2012.04.003.

439 [42] Fayers PM, Machin D. Quality of Life. Third Edit. Blackwell Publishing Ltd; 2016.

440 [43] Wheelwright S, Bjordal K, Bottomley A, Gilbert A, Martinelli F, Pe M, et al. EORTC Quality of Life
441 Group Guidelines for Developing Questionnaire Modules 2021.

442 [44] Amsterdam Public Health. COSMIN Tools 2024. https://www.cosmin.nl/tools/checklists-assessing-
443 methodological-study-qualities/ (accessed August 15, 2024).

444 [45] Terwee CB, Prinsen CAC, Chiarotto A, Westerman MJ, Patrick DL, Alonso J, et al. COSMIN
445 methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study.
446 Qual Life Res 2018;27:1159–70. https://doi.org/10.1007/s11136-018-1829-0.

447 [46] Mokkink LB, Terwee CB, Prinsen CA, Chiarotto A, Cw De Vet H, Bouter LM, et al. COSMIN
448 methodology for assessing the content validity of PROMs: User manual. Circulation 2018;120:0–70.

449 [47] Badarudeen S, Sabharwal S. Assessing Readability of Patient Education Materials: Current Role in
450 Orthopaedics. Clin Orthop Relat Res 2010;468:2572–80. https://doi.org/10.1007/s11999-010-1380-y.

451 [48] Lorente S, Viladrich C, Vives J, Losilla JM. Tools to assess the measurement properties of quality of
452 life instruments: A meta-review. BMJ Open 2020;10. https://doi.org/10.1136/bmjopen-2019-036038.

453 [49] John. Foundations of oral health-related quality of life. J Oral Rehabil 2020;48:355–9.
454 https://doi.org/https://doi.org/10.1111/joor.13040.

455 [50] Rogers SN, Semple C, Babb M, Humphris G. Quality of life considerations in head and neck cancer:
456 United Kingdom National Multidisciplinary Guidelines. J Laryngol Otol 2016;130:S49–52.
457 https://doi.org/10.1017/s0022215116000438.

458 [51] Garner SJ, Patel S, Pollard AJ, Jerreat MP. Post-treatment evaluation of oral health-related quality of
459 life in head and neck cancer patients after dental implant rehabilitation. Br Dent J 2023:1–10.
460 https://doi.org/10.1038/s41415-023-5460-2.

461