



Current Concepts and Considerations in Measuring Dysphagia-Related Quality of Life for People with Head and Neck Disease

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Abstract

Purpose of Review To provide an overview of current concepts and considerations in the measurement of dysphagia-related quality of life (QoL) for people with head and neck disease. We describe key psychometric and other tool properties that are important to consider when deciding which dysphagia QoL tool to use in practice. The review seeks to establish which tool/s best meet the required properties.

Recent Findings Currently, no single dysphagia QoL tool meets all criteria. However, a few (SWAL QoL, MDADI, SOAL) meet several parameters and we highlight the current evidence base for these assessments.

Summary QoL is essential to providing holistic clinical care and could also be an important outcome in research when evaluating interventions. Existing tools may benefit from re-validation studies which take account of progress made in the fields of instrument development, cross-cultural validity and patient centredness. It is also crucial to recognise that the value of capturing QoL in clinical practice is only realised by subsequent follow-up with the individual patient.

Keywords Dysphagia · Quality of life · Outcome measurement · Head and neck cancer · ENT

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Introduction

Treatment for head and neck cancer and ear nose and throat (ENT) conditions often result in persistent and complex dysphagia [1]. Research suggests that having dysphagia contributes to poorer self-reported quality of life outcomes (QoL) [2] and that people rate swallowing as one of their highest concerns after treatment [3].

Collecting QoL outcomes offers opportunity to tailor treatments and rehabilitation goals for the individual. This includes providing appropriate symptom management and care that might otherwise not be communicated to the healthcare team [4]. Measures can be repeated periodically, monitoring changes and facilitating the identification of both improvements and decline in the individuals' perceptions. However, with a multitude of self-reported tools available we offer key definitions, review the psychometric properties of the commonly used QoL tools, consider their application and make suggestions for further developments in research and practice.

Background

Definitions of QoL

The World Health Organisation (WHO) [5] define QoL as ‘An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships’.

Health-related quality of life (HR-QoL) refers to the impact of disease, illness and treatment on QoL domains [6] The term functional health status (FHS) captures an individual’s ability to perform normal daily activities (for example eating and drinking) to meet basic needs, fulfil usual roles and maintain health and well-being [7]. A FHS questionnaire for dysphagia might seek to quantify the severity of specific dysphagia symptoms as they impede *functioning* and is therefore distinguishable from the concept of HR-QoL [7].

Toward a Working Definition of Dysphagia-Related QoL

When individuals experience changes or difficulties in eating, drinking and swallowing, it is frequently reported as a high-impact concern [3]. Individuals who experience sudden loss of this critical function following oncological or surgical treatments for head and neck/ENT disorders may have different experiences to those with different degenerative aetiologies, influenced by personal, cultural, and contextual circumstances [8]. Recovery and adaptation to functional challenge also influence people’s perception of their compromise. Dysphagia-related QoL is therefore highly time-dependent and framed by personal expectations, not just the preceding disease and/or its treatment. Indeed, quantifiable swallowing function is not always directly associated with patient-reported QoL further underlying these conceptual differences.

We suggest dysphagia-related quality of life (QoL) might be described as follows: how an individual perceives the impact of any difficulty they have with eating, drinking and swallowing, on their physical, mental, emotional and social functioning relative to their unique situation, culture, goals, expectations and concerns at any given time.

A simple way for clinicians to assess QoL is a questionnaire or patient-reported outcome measure (PROM). Table 1 gives examples of the different types of PROM from the generic to the specific.

Table 1 Example of a generic, health-related, and disease-specific QoL questionnaire

Generic e.g. WHOQoL-100	Health related e.g. EuroQoL (EQ-5D)	Disease specific e.g. EORTC QLQ-C30	Symptom specific e.g. SWAL-QoL	Symptom and disease specific e.g. MDADI
Can be administered to everyone regardless of health status. Some generic questionnaires are culturally specific, others have been cross-culturally validated.	Can be applied to patients with any disease. Some can be administered to healthy individuals. Sometimes used for comparison between patient groups. Often used for health economic assessment.	Questions relevant to a particular disease. Usually contains general items of QoL Used for evaluating new treatments when effect on QoL is uncertain.	Questions ideally co-developed by people with the symptom. Specific detail about symptoms and impact on QoL	Considers specifics of how a disease can lead to a symptom. Consideration of QoL in that context.

Current Topics in Dysphagia Related-Quality of Life Measurement

Frameworks for Assessing Psychometric Robustness

PROMs are often included in a battery of measures that individuals are asked to complete as part of their care. However, selecting the appropriate PROM can be time-consuming and may be influenced by clinician and institutional preferences [9]. At the time that this article was written, research was underway to summarise and comprehensively assess the psychometric properties of the dysphagia-related PROMs available for the HNC population using COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) methodology [10]. Several tools have been developed to assess the psychometric properties of PROMs including the COSMIN risk of bias checklist, the patient-reported outcomes measurement information system (PROMIS) and the international society for QoL research (ISOQOL) recommendations [11–14]. However, the COSMIN Risk of Bias Checklist remains the most frequently used and includes items identified in other tools [12]. The COSMIN checklist was developed using a systematic literature review and an iterative Delphi process. Following expert discussion and pilot testing the COSMIN group developed guidelines for the assessment of content validity. Psychometric properties included in the COSMIN checklist are content validity, internal structure, reliability, measurement errors, criterion validity, hypothesis testing for construct validity and responsiveness [13].

Psychometric Properties for Clinical Consideration

Reliability, Responsiveness and Interpretability

Assessment of reliability establishes the stability of a PROM during repeat testing and includes the assessment of internal consistency and test–retest reliability. Internal consistency refers to the assessment of whether items within a PROM correlate and measure the same construct. Test–retest reliability indicates the consistency of results of a PROM when it is repeated after an appropriate interval and in the absence of any change in the condition/disease status or any treatment interventions. It also includes inter- and intra-rater reliability. Assessment of responsiveness establishes the ability of the PROM to detect change over time and in response to changes in disease status and or specific interventions. Assessment of interpretability provides information as to whether results of a PROM can be easily understood. This includes information regarding

(1) minimally important change, a measure reflective of the lowest change in score that correlates with a meaningful perceived change for an individual, (2) floor and ceiling effects which refers to the frequency in selection of the top or bottom end of the response scale and (3) distribution of scores where ideally at least 75% of items should fall between 1 and – 1 (normal distribution) [13, 14].

Validity

Assessment of validity provides information on the degree to which a PROM reflects the construct it intends to measure. This includes the assessment of construct validity—the extent to which a PROM score is consistent with the hypothesis. This also needs to consider differences between groups and cross-cultural validity. Criterion validity considers whether the PROM accurately reflects a gold standard—which is difficult to assess for dysphagia-related QoL in people with HNC [13].

Content validity relates to whether the content of the PROM accurately measures what the tool is designed to measure [12]. For the purposes of this discussion, that construct is dysphagia-related QoL in people with HNC. The key elements of content validity are relevance, simplicity and how thorough a tool is at capturing information about the construct and population being assessed [15]. Content validity is assessed using robust qualitative methods, unlike criterion and construct validity, and has been shown to be the least included property in published validation studies of HN dysphagia QoL measures [16•].

Face validity is the first consideration for content validity, referring to the immediate sense when looking at a tool as to whether it does reflect the construct to be measured [12]. It is a subjective concept, but underpins the overall value of content validity, since if the questions in a PROM measuring dysphagia-related QoL do not resonate with the person completing the measure, or the clinician using it, it is unlikely to be considered of value [16•]. The most popular dysphagia-related QoL measures demonstrate good face validity [17], hence their functionality and use in clinical practice (MDADI, SWAL-QoL).

The process of completing robust content validation involves five clearly defined steps according to COSMIN methodology [18] and are outlined in Table 2 below for dysphagia-related QoL.

Content validity is regarded as the most important psychometric aspect of any PROM [13, 15]; however, the key step of involving patients and service users in the process of tool development is frequently not completed or reported [7, 19]. Their unique perspective allows patients or service users to identify items for inclusion in a PROM that would not be considered otherwise. It is also important that engagement

Table 2 Content validation according to the COSMIN methodology

Step	Applicability to a dysphagia related QoL
Information about the construct and situation measured has been reviewed and reported	- Clarify what is meant by dysphagia related QoL for the purposes of the tool - Consider existing conceptual models such as the one described by Timmerman et al. [17], Patel et al. [9] or Manduchi et al. [10]
Include information about the content of the tool	- Example of the tool/questionnaire provided in the article - Explanation of how the questionnaire was developed included
Expert panel involved in review and validation	- Were patients involved at every stage? - Were dysphagia experts who were not involved in the tool development involved, for example as part of Delphi study?
Content matches the construct (relevance/comprehensibility)	- User testing by people living with dysphagia
A framework/strategy is used to match the tool to the construct	- More relevant for measures where there is wide choice - An example for dysphagia QoL would be using the WHO ICF to compare content across potential questionnaires

with people who have experience of the construct are from a fully representative population, particularly in dysphagia-related QoL in HNC and ENT which is experienced by a diverse demographic. As in all robust qualitative research, this requires purposive sampling of the expert panel involved in tool development to capture a full range of characteristics [13, 14]. However, stakeholder involvement is often limited to engagement with clinical experts for their opinions and input. Whilst this is an important aspect of content validity [11], it overlooks the value of involving people with lived experience of the construct being tested. This has significant implications for existing tools to measure dysphagia-related QoL as they risk not measuring the most relevant issues for people living with dysphagia. Terwee et al. [15] have developed a checklist for the assessment of content validity in PROMs which, although not specifically designed to be used with dysphagia-related QoL in HNC/ENT may be useful to evaluate whether existing measures have robustly completed content validation.

Finally, content validity needs to take into account cross-cultural considerations particularly when tools are being used in a culture or language separate from their development origin. For example, the MDADI has been translated into approximately 12 different languages; however, these have all been direct translations and do not account for the differences in dysphagia-related QoL in other cultures where the parameters may be very different.

Clinical Utility

There are numerous facets to the design and content of a tool which have potential to have a significant impact on the success of its use in practice, and therefore also the meaningfulness of the results a tool produces [20]. As suggested by Lorente et al. [21], tools designed to measure QoL need to be ‘usable’ in practice; however, current published formal assessments of specific dysphagia-related

QoL tool strengths, weaknesses and rigour do not consistently consider this alongside more traditional psychometric assessments.

Tool ‘usability’ incorporates multiple parameters of tool properties that affect their use in practice, for both patients and clinicians. Criteria that constitute important aspects of tool usability have been explored through both primary qualitative research and through review and synthesis of existing literature. This is still a developing area, and some parameters may overlap with content validity concerns: boundaries between content validity and clinical utility have yet to be defined.

Assessment and analysis of parameters that combine to make tools ‘feasible’ is a case of qualitative appraisal, as for content validity, rather than mathematical psychometric assessment. The COSMIN group describe these as ‘pragmatic characteristics’, but the reality of the current literature base is that there is not yet one agreed term to name these factors.

These ‘pragmatic’ or ‘feasibility’ characteristics of a tool have been defined in various ways in the existing PROM literature. Many acknowledge that these aspects of a tool have strong clinical significance, but as yet there is no formal guidance to define which parameters comprise feasibility, and how to assess a tool’s strengths and weaknesses with respect to these parameters. Commonly recurring themes are tool length and time taken to complete [22–24], literacy level [9, 25], time taken to score [26, 27] and accessibility issues such as availability of translations and copyright-free versions of the tool [9, 25, 28].

Patel et al.’s [9] systematic review of PROMs in dysphagia develops these concepts, considering scoring, interpretation, burden, and presentation in their tool assessments alongside more traditional parameters. They highlight tool length and readability as significant properties of a tool, emphasising potential issues in these respects with tools commonly used in HNC/ENT dysphagia practice such as the SWAL-QoL and MDADI.

Formal in-depth assessment of these ‘usability’ properties in dysphagia-related QoL outcomes tools commonly used in HNC/ENT have not been undertaken to date. In addition, usability parameters are rarely mentioned in the validation papers for commonly used dysphagia QoL measurement tools.

Clinical utility is likely to be as important a criterion as psychometric rigour: if a tool designed to assess dysphagia-related quality of life is not practicably or physically usable by clinicians and individuals in the context of busy clinical practice, with a range of different abilities and backgrounds, then its application will be limited. Usability data is currently lacking for commonly used tools.

Commonly Used Tools and Their Psychometric Properties

General Dysphagia-Related QoL Questionnaires

The SWAL-QOL is a general dysphagia-related QoL questionnaire with established reliability and validity in patients with dysphagia including those with head and neck cancer (HNC) [29–31]. The Sydney Swallow Questionnaire (SSQ) is predominately an assessment of functional health status but includes items assessing dysphagia-related QoL [32]. Research into the psychometric properties of this tool has generated conflicting results; the use of classical test theory statistical methods demonstrated that the SSQ has strong content, construct, discriminant and predictive validity and test–retest reliability [33, 34]. However, Cordier et al.’s analysis of the tool using an item response theory statistical approach uncovered issues with the structure of the tool [35•].

Existing dysphagia-related QoL PROMs are limited by significant differences in terms of developmental rigour and a lack of information regarding the tool development [9, 17]. This makes it difficult to compare scores between different tools. Other factors complicating the comparison of results of existing dysphagia-related QoL tools are differences in the number and types of domains and varying number of items contained within each PROM. The psychometric robustness of existing tools is compromised by the lack of information regarding scoring and interpretation of scores, responsiveness and respondent burden [17]. These factors complicate the selection of the most appropriate PROM for clinical practice and research [10, 36]. As a result, PROMs are frequently selected based on clinician preference rather than psychometric properties [10].

Head and Neck Cancer Dysphagia-Related QoL

The MD Anderson Dysphagia Inventory (MDADI) was developed to assess dysphagia-related QoL in the HNC population [32, 37, 38]. The MDADI original validation paper [37] suggests good internal consistency, test–retest

reliability, criterion and construct validity and, more recently data to support a minimally clinically important difference (MCID) score has been published [39, 40•]. However, recent research by Lin et al. has demonstrated item redundancy within the tool [40•]. The Swallowing Outcomes After Laryngectomy (SOAL) questionnaire is an assessment of dysphagia burden in the post-laryngectomy population. Inclusion of a ‘bother’ score provides an indication of dysphagia-related QoL. The SOAL has been shown to have good clinical utility, reliability, content and construct validity, can discriminate between groups with known differences in swallow function and relates to instrumental findings [41–43].

Timmerman et al.’s systematic review [17] considered the content validity of four dysphagia-related QoL measures (not specific to HNC/ENT populations). Based on COSMIN criteria, they determined that only the SWAL-QOL had a positive rating for content validity, and the MDADI did not report their content validity process in enough detail to score. By contrast, a more recent study by Patel et al. [9] used a checklist developed by their own team [44] that scored both the MDADI and the SWAL-QOL highly for content validity, indicating that the tool used to assess psychometric rigour also needs to be taken into account in any assessment.

However, the SWAL-QoL, MDADI and SOAL did clearly involve patients in the development of the tools—the MDADI using four focus groups with 4–8 people with HNC-related dysphagia in each [37] to sense check and review the wording of questionnaire items as well as ‘share their life experiences regarding dysphagia’. However, this aspect of the methods is not explored further in either the results or the conclusions of the paper, and it is difficult to determine how the patient involvement altered the tool. By comparison, the SWAL-QOL development used focus groups with patients with dysphagia (non-HNC related) and caregivers to generate the items that were then used as the prototype questionnaire [31]. Similarly, the initial development of the SOAL used focus groups with laryngectomy patients to item generate [41] and for preliminary content validation; however, the main psychometric validation of SOAL was not published at the time of the Timmerman review (2014).

The MD Anderson Dysphagia Inventory (MDADI) [37], the SWAL-QoL [31] and the Head and Neck Cancer Survivors’ Assessment of Mealtimes (HNSAM) [45] do not note any consideration of usability parameters in their development. However, subsequent work by others have highlighted the importance of literacy levels when selecting and appraising PROMs and looked at the readability of tools [40•, 46]. The MDADI was considered the most difficult-to-read tool, requiring a ‘college level’ of literacy [46]. Tool length is another parameter frequently highlighted in the literature as a property that can ‘make or break’ how usable

a tool is in clinical practice. Many commonly used tools in HNC/ENT SLT practice are long: the MDADI has 20 items and the SWAL-QOL has 44 items. To address this issue using existing tools, Lin and colleagues [40•] developed the ‘miniDADI’—a five-item reduced form of the MDADI which they suggest has comparable validity with the initial MDADI validation.

Research Priorities

In our view, dysphagia outcome measurement will benefit from the creation and implementation of a standardised set of clinical utility assessment criteria as an adjunct to psychometric assessment criteria. The results of a combined analysis would provide valuable data for clinicians who wish to choose a dysphagia QoL tool which is not only psychometrically robust but also easy to use. Existing tools should be appraised in terms of their ‘usability’ to facilitate clinicians’ decision-making process when choosing which tool to use in a busy clinical environment. Length, layout and readability cannot be changed without altering the inherent psychometric properties of the tool itself meaning that any changes to tools require revalidation to ensure they adequately meet all psychometric properties, content validity and usability.

In addition, a more robust process to the revalidation of the tools in regular clinical and research use is recommended including consideration of modern statistical methods such as item response theory, and potentially the addition of further qualitative data to support substantiation of content validity from a service user perspective.

Another key research priority is how QoL is understood across different cultures and whether tools can truly be ‘translated’ when they are applied to different communities and are assessing something that is so culturally specific and sensitive. A systematic review of QoL research in medicine and health sciences reported that most QoL studies occur in developed countries in the West [4] risking significant bias to current measures. Future work needs to consider all demographics to truly capture QoL in a sensitive way.

Conclusion

Dysphagia-related quality of life is a key component of head and neck treatment outcomes. Many tools exist and clinicians require confidence and competence in choosing, administering, interpreting and applying the findings to inform care and rehabilitation. Guidance is available to support this process such as the AHP outcome measures selection tool [46], which may help practitioners to choose the right tool at the right time, for the right individual. Ultimately, the utility of these tools must be recognised as part of a wider philosophical and scientific perspective which

places the individual at the centre of all elements of their clinical interventions and recognises the value of both qualitative and quantitative approaches to understand this complex issue. Clinicians should recognise current tools to measure dysphagia-related QoL in HNC or ENT populations have great potential value but cannot be used in isolation and must form part of a holistic person-centred approach to care to have the most efficacy.

Declarations

Conflict of Interest The authors declare no competing interests.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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