

## Functional Health Status in Oropharyngeal Dysphagia

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### ABSTRACT

Patient self-evaluations on Functional Health Status (FHS) questionnaires are considered to be part of the assessment of oropharyngeal dysphagia. FHS questionnaires capture the unique personal perception of someone's health, taking into account social, functional and psychological factors. Many FHS questionnaires have been reported on in literature. This paper describes a selection of FHS questionnaires in more detail; issues concerning the inclusion of Health Related Quality of Life (HRQOL) items, choices in target populations and the distinction between oropharyngeal versus esophageal dysphagia will be discussed. Recommendations are made about the evaluation and use of FHS questionnaires in daily clinical practice. In particular the psychometric properties of FHS questionnaires should be evaluated to determine if they meet quality criteria for measurement properties of health status questionnaires in order to guarantee valid and reliable outcome measurements.

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**Key words:** Oropharyngeal dysphagia; Deglutition disorders; Swallowing disorders; Functional health status; Questionnaire;

Patient self-evaluation

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### INTRODUCTION

#### Prevalence of oropharyngeal dysphagia

Oropharyngeal dysphagia or deglutition disorders are associated with increased risk of dehydration, malnutrition, aspiration pneumonia and high mortality rates. Dysphagia has also been found to have a major impact on a patient's health related quality of life<sup>[1,2,3]</sup>.

The reported prevalence of oropharyngeal dysphagia varies depending on the described subject population. Elderly subjects are at higher risk for oropharyngeal dysphagia due to impaired efficacy and safety of the swallow caused by weak tongue propulsion and prolonged and delayed swallow response<sup>[4]</sup>. Turley *et al*<sup>[5]</sup> estimated the prevalence of oropharyngeal dysphagia to be 13.7% based on surveys data of independent-living members of retirement communities. Conversely when studying the outcome of a swallow screening using different bolus viscosities among elderly in urban nursing homes, prevalence increased up to 52.7%<sup>[6]</sup>. Martino *et al*<sup>[2]</sup> found prevalence of approximately 55% in acute stroke patients admitted to a hospital. In summary, oropharyngeal dysphagia is a common condition, particularly among the elderly and patients with neurological diseases<sup>[7]</sup>.

The reported prevalence of oropharyngeal dysphagia among the general population varies between 2.3%<sup>[8]</sup> and 12.9%<sup>[9]</sup>. Inconsistencies in prevalence data may be the result of using different definitions of oropharyngeal dysphagia. For instance, Rofes *et al*<sup>[4]</sup> defines oropharyngeal dysphagia as difficulty or discomfort during the progression of the alimentary bolus from the mouth to the stomach, whereas Martino *et al*<sup>[10]</sup> defines oropharyngeal dysphagia as any abnormality in swallowing physiology of the upper aerodigestive tract. In the process of retrieving prevalence data on dysphagia, Chiocco *et al*<sup>[9]</sup> based their study inclusion criteria on subjects' confirmation or denial of having "a feeling that food sticks in the throat or chest". Additional factors that may also have contributed to variation in prevalence data include different and

inconsistent use of terminology which can lead to misinterpretation when comparing study outcomes; for example, there is great inconsistency in terminology used for texture-modified foods and thickened liquids used in dysphagia management<sup>[11]</sup>. Furthermore, distinct choices of measurement tools, outcome variables and cut-off points for determining abnormality in swallowing may add to the confusion when calculating and interpreting prevalence rates of oropharyngeal dysphagia<sup>[12]</sup>. Finally, different and inconsistent definitions, criteria, and terminology used to determine the presence or absence of oropharyngeal dysphagia impacts on the accuracy of prevalence data.

### Treatment and management

As awareness of the impact of oropharyngeal dysphagia on patients' health increases, so rises the demand for appropriate treatment and management of dysphagia. Depending on the outcome of the assessment, treatment may include medical, surgical, and/or behavioural options<sup>[13]</sup>. Medical options refer to dietary modifications when underlying diseases are present (e.g., diabetes) or pharmacological treatment (e.g., antireflux medication). Surgical interventions aim to improve the glottal closure or optimise the pharyngo-esophageal segment opening. The third option focuses on treatment by dysphagia or speech therapists using a variety of behavioural techniques including: bolus modification, sensory and motor behavioural techniques, postural adjustments, swallow manoeuvres, and the application of biofeedback to facilitate motor learning processes<sup>[14]</sup>.

### Screening and assessment

Treatment outcomes need to be objectified; it is widely accepted that both medical treatments and interventions by allied health professionals should be evaluated according to scientific methods and standards of evidence-based medicine. This requires the use of valid and reliable screening and assessment. Usual practice dictates that after failing the initial screening for oropharyngeal dysphagia, patients will be referred for further clinical assessment. Although videofluoroscopic and fiberoptic endoscopic evaluation of swallowing are considered gold standards in the assessment of dysphagia, a wide range of assessment tools and patient self-evaluation questionnaires exist and are used in daily practice. Typical clinical assessment of dysphagia may include: medical and patient history taking; assessment of cognition and communication abilities; evaluation of the oral, laryngeal and pharyngeal physiology, anatomy and functioning (including cranial nerve examination); and evaluating oral intake<sup>[12]</sup>. Patient self-evaluations are self-administered questionnaires and cover two different constructs: Health Related Quality of Life (HRQOL) and Functional Health Status (FHS). HRQOL refers to the unique personal perception of someone's health, taking into account social, functional and psychological issues. FHS refers to the influence of a given disease on particular functional aspects and aims to quantifying the symptomatic severity of that disease (e.g., oropharyngeal dysphagia) as experienced by the patient<sup>[15]</sup>. Many patient self-evaluations combine both disease-related functioning and quality-of-life, even though FHS and HRQOL are considered two distinct constructs.

In addition to the above-mentioned methods, a number of other evaluation techniques are available for assessment of dysphagia; for example, oxygen desaturation, videomanometry, endoscopic ultrasound, electromyography, esophageal Ph monitoring and scintigraphy. Some of these methods are commonly used, whereas other techniques are less frequently applied and restricted to

experimental settings. The choices of screening and assessment methods are influenced by factors related to workplace setting, research, clinician's preference and expertise, as well as by criteria on reliability and validity<sup>[12]</sup>.

## FUNCTIONAL HEALTH STATUS QUESTIONNAIRES

### Measurement of FHS

The evaluation of a patient's FHS is considered to be part of the full assessment of patients with oropharyngeal dysphagia and enables medical and allied health professionals to take into account the functional aspects and symptom severity of the swallowing disorder. Different techniques are used to retrieve relevant information on a patient's FHS; patient interviews and/or patient self-evaluation questionnaires are commonly used in clinical practice. Of those options, using a patient self-evaluation questionnaire is often the preferred choice, because the method of data collection is more structured and standardised compared with an interview. Both the needs of the health care professionals and those of the patient will influence the choice of which questionnaire will be included during the process of clinical assessment.

Due to common time constraints in clinical practice, a questionnaire needs to be concise and quick to administer, thus restricting the number of items and patient involvement. Furthermore a questionnaire should be easy to administer and score and cover all the essential aspects of FHS. Moreover, assessments need to be valid and reliable. Data collected with measurement tools that show indeterminate or poor measurement properties will distort the assessment outcomes. Therefore self-evaluation FHS questionnaires should demonstrate sound psychometric properties. To this effect Terwee *et al.*<sup>[16]</sup> developed quality criteria for measurement properties of health status questionnaires that are widely used across medical and allied health professions.

Several different FHS questionnaires are currently being used in clinical practice. A selection of questionnaires will be discussed in more detail and are considered to be a representative sample following a comprehensive literature search on FHS questionnaires. An introductory overview is provided in table 1. Most of the described questionnaires in this table are originally developed in English: the Dysphagia Handicap Index<sup>[26]</sup>, the Eating Assessment Tool (EAT-10)<sup>[17]</sup>, the Dysphagia Disorder Survey (DDS)<sup>[25]</sup>, the M.D. Anderson Dysphagia Inventory (MDADI)<sup>[20]</sup>, the Sydney Swallowing Questionnaire (SSQ)<sup>[22]</sup>, the Swallowing Outcome after Laryngectomy (SOAL)<sup>[23]</sup> and the Mayo Dysphagia Questionnaire-30 (MDQ-30)<sup>[24]</sup>. Some of the FHS questionnaires were originally developed in other languages, such as the Dysphagia Short Questionnaire (DSQ)<sup>[27]</sup> in Swedish, the DYsphagia in MULTiple Sclerosis Questionnaire (DYMUS)<sup>[18]</sup> in Italian, the Swallowing Disturbance Questionnaire (SDQ)<sup>[21]</sup> in Hebrew, and the Deglutition Handicap Index<sup>[28]</sup> in French.

Although this manuscript focuses on FHS, many questionnaires include items on HRQOL as well, thus combining two different constructs in a single assessment. When using these questionnaires, outcome data will represent an overall rating of a patient's self-perception in which constructs of FHS and HRQOL are fused and cannot easily be disentangled. Some questionnaires represent mainly FHS and include one or a few additional items on HRQOL (e.g., EAT-10, DDS, DSQ, DYMUS, MDQ-30, SDQ, SOAL and SSQ), whereas the MDADI, the Dysphagia Handicap Index and the Deglutition Handicap Index focus both on both FHS and HRQOL,

**Table 1** Overview of selected Functional Health Status questionnaires.

Author(s) in alphabetical order	Questionnaire <sup>1</sup>	Acronym	Scales (Number of items)	Range of score	Target population
Belafsky <i>et al</i> <sup>[17]</sup> , 2008	Eating Assessment Tool	EAT-10	- One scale (10 items)	0-40	Adults at risk of dysphagia
Bergamaschi <i>et al</i> <sup>[18]</sup> , 2008	DYSphagia in MULTiple Sclerosis Questionnaire	DYMUS	- Dysphagia to solid (7 items) - Dysphagia to liquid (3 items)	0-10	Adults with Multiple Sclerosis
Calis <i>et al</i> <sup>[19]</sup> , 2008	Parent questionnaire on subjective feeding experience	N/A	- One scale (3 items)	N/A	Children with severe generalized cerebral palsy and intellectual disability
Chen <i>et al</i> <sup>[20]</sup> , 2001	M.D. Anderson Dysphagia Inventory	MDADI	- Global (1 item) - Physical (8 items) - Functional (5 items) - Emotional (7 items)	20-100	Adults with Head and Neck Cancer
Cohen and Manor <sup>[21]</sup> , 2011	Swallowing Disturbance Questionnaire	SDQ	- Related to oral phase (5 items) - Related to pharyngeal phase (10 items)	0.5-44.5	Adults with Parkinson Disease
Dwivedi <i>et al</i> <sup>[22]</sup> , 2010	Sydney Swallowing Questionnaire	SSQ	- One scale (17 items)	0-1700	Adults with oral cavity and oropharyngeal cancer
Govender <i>et al</i> <sup>[23]</sup> , 2012	Swallowing Outcome after Laryngectomy	SOAL	- One scale (17 items)	0-34	Adults with total laryngectomy
Grudell <i>et al</i> <sup>[24]</sup> , 2007	Mayo Dysphagia Questionnaire	MDQ	Total number of items (stem-and-leaf format): 27 - Dysphagia - Heartburn - Acid regurgitation - Dysphagia related to particular foodstuffs or consistencies - Other	N/A	Adults with reflux esophagitis and/or reflux peptic stricture <sup>2</sup>
Sheppard and Hochman <sup>[25]</sup> , 1988	Dysphagia Disorders Survey	DDS	- Related factors to dysphagia (7 items) - Dysphagic symptoms (6 items)	0-36	Children and adults with intellectual and developmental disabilities
Silbergleit <i>et al</i> <sup>[26]</sup> , 2012	Dysphagia Handicap Index	DHI	- Physical (9 items) - Functional (7 items) - Emotional (9 items)	0-100	Adults with dysphagia
Skeppholm <i>et al</i> <sup>[27]</sup> , 2012	Dysphagia Short Questionnaire	DSQ	- One scale (5 items)	0-18	Adults after anterior cervical spine surgery
Woisard <i>et al</i> <sup>[28]</sup> , 2006	Deglutition Handicap Index	DHI	- Physical (10 items) - Functional (10 items) - Emotional (10 items)	0-120	Adults with dysphagia

<sup>1</sup> The MDADI, the Deglutition Handicap Index and the Dysphagia Handicap Index cover both FHS and HRQOL, whereas all other questionnaires mainly focus on FHS.

<sup>2</sup> Information provided by the corresponding author.

thus representing an overall combined score of the patient's self-perception on FHS and HRQOL. More details on these latter questionnaires can be found in the systematic review on HRQOL questionnaires by Timmerman *et al*<sup>[29]</sup>.

### FHS questionnaires in oropharyngeal dysphagia

The following six patient self-evaluation questionnaires describe FHS in oropharyngeal dysphagia:

(1) The Eating Assessment Tool (EAT-10)<sup>[17]</sup> focuses mainly on FHS, and is a self-administered questionnaire for the subjective assessment of dysphagia. The single-scaled assessment includes 10 items using 5-point scales resulting in a total score range of 0 to 40. A score of 3 or higher indicates a problem in the swallowing process. The EAT-10 is designed to be used in a broad range of dysphagic patient populations to assess symptom severity, quality of life, and treatment efficacy<sup>[17]</sup>.

(2) The Dysphagia Short Questionnaire (DSS)<sup>[27]</sup> also employs a, a single scale, and has five items. The questionnaire aims to assess the dysphagia severity over time in a target population of patients following anterior cervical spine surgery. A total score is calculated by summing up the individual item scores to a maximum of 18. Higher scores are associated with increased clinical severity grades<sup>[27]</sup>.

(3) The DYSphagia in MULTiple Sclerosis questionnaire (DYMUS)<sup>[18]</sup> is designed to assess the swallowing functions of patients with Multiple Sclerosis. The ten dichotomous item questionnaire consists of two scales: the 'Dysphagia to solid'-scale

(seven items) and the 'Dysphagia to liquids'-scale (three items). The total score range from 0 to 10; higher scores indicate a more severely impaired deglutition function<sup>[18]</sup>.

(4) The Swallowing Disturbance Questionnaire (SDQ)<sup>[21]</sup> has fifteen items in total and contains two different scales. The first scale has five items related to the oral phase of swallowing and the second scale has ten items related to the pharyngeal phase of swallowing. The minimum score of the SDQ is 0.5 and the maximum score is 44.5. A SDQ score of greater than 12.5 is considered to be a good predictor of the presence of both known and undiagnosed swallowing disturbances<sup>[21]</sup>.

(5) The Swallowing Outcome after Laryngectomy (SOAL)<sup>[23]</sup> consists of a single scale with 17 items (score 0-2) and is designed to assess swallowing function post-total laryngectomy. The minimum score of the SOAL is 0 and the maximum is 34. Higher scores imply more severely impaired swallowing<sup>[23]</sup>.

(6) The Sydney Swallowing Questionnaire (SSQ)<sup>[22]</sup>, is a single-scaled questionnaire consisting of 17 questions specifically designed to evaluate oral and pharyngeal phase impairments of swallowing. The minimum score of the SSQ is 0 and the maximum is 1700. Higher scores indicate a more severely impaired swallowing function<sup>[22]</sup>. The authors consider the questionnaire to be a valuable tool in evaluating and managing dysphagia in oral cavity and oropharyngeal cancer patients.

Some of the questionnaires described above target specific patient populations. These questionnaires may include disease-specific items whereas other surveys such as the EAT-10 have been developed for

a more generalised population at risk of oropharyngeal dysphagia. A few questionnaires do not focus on the patient directly, but instead target parents, spouses or health care providers. One of the reasons for not using a patient self-administered questionnaire is when patients have difficulties in comprehension or lack sufficient cognitive capacities to provide adequate information. In those cases the patient's health care providers or spouses can be a possible source of information on their FHS. The same proxy reporting applies when young children or adolescents with intellectual disability are involved. In those situations the parents would be an indispensable source of information on a child's daily routine, special needs and coping mechanisms in regard to eating strategies and possible swallowing difficulties. The following two are examples of such indirect reporting:

(1) The Dysphagia Disorders Survey (DDS)<sup>[25]</sup> was developed for the screening of oral preparatory, oral and pharyngeal dysphagia in residential populations with severe and profound intellectual disabilities. The questionnaire consists of two parts. The first part (7 items) summarises factors associated with dysphagia: modifications of diet consistency, use of adaptive utensils, feeding dependence, body postural control, and use of special feeding techniques. The second part (6 items) probes for neuromotor functions involved in deglutition: oral preparatory stage management of solid and liquid boluses, oral and pharyngeal stage symptoms of impaired posterior containment, and impaired pharyngeal transit of the food bolus. The questionnaire is used by speech pathologists during mealtime observation of the patient. The range of possible scores varies between 0 and 36; higher scores indicate signs of dysphagia and more severely impaired deglutition<sup>[25]</sup>.

(2) Calis *et al*<sup>[19]</sup> developed a three-item questionnaire on subjective feeding experiences for more detailed information on the presence of feeding problems, pleasure of eating, and average mealtime duration as evaluated by parents and caregivers during a child's mealtime. Possible answers ranged from '(almost) never' to '(almost) always' for the first and the second question, and from 'less than 15 minutes' to 'more than 45 minutes' for the third item. This questionnaire may provide useful, but very limited information on a child's FHS.

When considering an indirect approach to gather FHS information and asking parents or health care providers to fill in any of the previously listed FHS questionnaires, and to close the gap in the child or patient's assessment process, it would be interesting to investigate possible differences between information provided by spouses or parents versus information provided by professional health care providers. Furthermore, it would be useful to examine if there are associations between FHS ratings by health care providers, spouses or parents versus patients' self-evaluations. The uniqueness of the health care provider's opinion lies within his or her professional background and their ability to evaluate a patient's functioning possibly more objectively compared with family members. Conversely, parents may spend much more time with their child, thus having a better overview of their daily functioning. In this regard, both parental and caregiver questionnaires may be considered to be complementary rather than redundant.

Finally, the difference between oropharyngeal dysphagia and esophageal dysphagia should be highlighted. Some confusion may exist in the literature about the terminology used. Although this manuscript focusses on oropharyngeal dysphagia, not all questionnaires make a clear distinction between oropharyngeal versus esophageal dysphagia. Some studies describe FHS in dysphagia without distinguishing between the two. Although the naming of these questionnaires may suggest otherwise, many 'dysphagia'

questionnaires actually target esophageal dysphagia, and therefore include items on gastroesophageal reflux. Below is an example of such a FHS questionnaire:

The Mayo Dysphagia Questionnaire (MDQ)<sup>[24]</sup> is a questionnaire designed for patients with reflux esophagitis and/or reflux peptic stricture. The name of the questionnaire may suggest dysphagia, but the target population is people with esophageal swallowing disorders. The MDQ is a 27-item instrument comprised of 25 items from previously validated Mayo Clinic instruments<sup>[3,30,31,32,33]</sup>, 1 item from the modified dysphagia scale<sup>[34,35]</sup>, and 1 new item on previous episodes of impaction. The questionnaire covers 3 symptom domains (dysphagia, heartburn and acid regurgitation) with 3 items per domain to detail symptom duration, frequency and severity. The MDQ also includes additional items on bolus consistency. Sixteen items are dichotomous, 9 items use a Likert scale, 1 item offers multiple non-hierarchical options, and the final item is a scale. Due to its stem-and-leaf format, a patient can answer as few as 13 or as many as 27 items<sup>[24]</sup>

## DISCUSSION AND CONCLUSIONS

While a multitude of FHS questionnaires are reported on in literature, not all questionnaires are suitable for use in daily clinical practice. Questionnaires should be easy to administer, not be time-consuming and target the subject population under study. When choosing a questionnaire to be used for any patient with oropharyngeal dysphagia, the selected questionnaire may include mainly generic items. Questionnaires that target a specific patient population are more likely to include more disease-specific items, thus eliciting more detailed information on the effects of a specific physical condition on a patient's FHS. Furthermore a distinction between oropharyngeal dysphagia versus esophageal dysphagia seems useful as the effects on FHS may differ substantially. The use of an overarching term such as dysphagia for both swallowing problems in the oropharyngeal or esophageal phase of the deglutition process is confusing and may lead to inappropriate choices of questionnaires. Furthermore, if items on HRQOL are combined with items on FHS in one single questionnaire, a distinction between the constructs may not be possible. There is a clear need to compare the reliability of ratings by spouses, parents, or health care providers with patients' self-evaluations.

When discussing the assessment of oropharyngeal dysphagia in general, videofluoroscopic and fiberoptic endoscopic evaluation of swallowing are considered to be the gold standards. In the area of HRQOL the SWAL-QOL<sup>[3]</sup> is usually referred to as the standard assessment tool<sup>[12]</sup>; however, no gold standard has been established for the assessment of FHS. The lack of a gold standard in measuring FHS restricts the comparability of treatment outcomes in intervention studies and data pooling when analysing the results of a meta-analysis contained within a systematic review.

However, in order to make decisions on which FHS questionnaire to choose as best evidence-based tool for the assessment of oropharyngeal dysphagia, the psychometric properties of each questionnaire should be determined according to the quality criteria for measurement properties of health status questionnaires, such as the one proposed by Terwee *et al*<sup>[16]</sup>. Criteria for properties such as content validity, internal consistency or reproducibility should be addressed. Only questionnaires with sufficient or good psychometric properties should be included in the assessment procedures. Questionnaires showing insufficient validity and/or reliability should not be considered as part of the assessment procedures as this will

lead to contamination and restricted interpretability of the results. It is beyond the scope of this paper to discuss the measurement properties for each questionnaire independently. However, Speyer *et al.*<sup>[36]</sup> provide an overview of data on psychometric properties of English FHS questionnaires as described in a systematic review. The authors conclude that in general the retrieved questionnaires receive poor or moderate psychometric ratings due to inadequate reporting of psychometric properties in literature. Furthermore, when questionnaires have proven to meet the psychometric quality criteria, simply accepting that the translated version meets the same psychometric quality criteria is incorrect. Differences may be induced through translations or by cultural issues. As such cross-cultural validation may be required. Cross-cultural validity refers to the degree to which the performance of the items on a translated or culturally adapted patient-reported outcome instrument is an adequate reflection of the performance of items in the original version of the instrument<sup>[37]</sup>. Therefore the instrument's psychometric properties may need to be re-assessed before implementing the questionnaire in scientific studies or daily clinical practice.

There is an urgent need for future research to focus on evaluating the psychometric properties of FHS questionnaires; missing data on measurement properties should be highlighted and evaluated<sup>[16]</sup>. If no FHS questionnaire meets the proposed quality criteria for measurement properties for a specific target population, then new questionnaires should be developed taking into account all of these criteria, thus creating valid and reliable outcome measurements of FHS.

## CONFLICT OF INTERESTS

There are no conflicts of interest with regard to the present study.

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