

HEALTH-RELATED QUALITY OF LIFE AND FUNCTIONAL HEALTH STATUS QUESTIONNAIRES IN OROPHARYNGEAL DYSPHAGIA

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Abstract: *Background:* Oropharyngeal dysphagia negatively affects the quality of life of patients. It may lead to malnutrition, dehydration, aspiration pneumonia and death, especially in older people. Dysphagia and its level of severity have to be assessed accurately and in a timely fashion, because only early intervention can prevent the onset of complications. There are numerous self-administered questionnaires to monitor both the severity of dysphagia and the effectiveness of therapeutic approaches. The objective of this article is to conduct a literature review and to illustrate the characteristics of various self-assessment questionnaires for oropharyngeal dysphagia. *Methods:* A search of observational studies of adult populations with dysphagia, published from 1990 to June 2014, was performed in the electronic database Pubmed. *Results:* A total of 23 self-assessment questionnaires, on Health-related Quality of Life and Functional Health status, were identified. Fourteen questionnaires were excluded from the analysis for the following reasons: the questionnaire was written in a language other than English or Italian (n=3); the questionnaire was specific for caregivers (n=1); the questionnaires were not specific for oropharyngeal dysphagia (n=10). Nine questionnaires, validated in adult populations, were examined. Only two self-assessment questionnaires on quality of life - DHI (Dysphagia Handicap Index) and SWAL-QOL (Swallowing Quality Of Life) - were correctly validated; other questionnaires had methodological errors. *Conclusions:* A specific self-assessment questionnaire for older adults was not found. Almost all of the currently available questionnaires need to be improved methodologically. Furthermore, new questionnaires specifically for older people should be developed.

Key words: Oropharyngeal dysphagia, self-reported questionnaires.

Introduction

Swallowing is the ability to transport solids and liquids, safely and effectively, from the oral cavity to the stomach (1, 2). Functionally, swallowing can be divided into three phases: the preparatory phase, which includes conscious effort to ingest food and reflexes in the oral cavity that help prepare the bolus to be swallowed; the transfer phase, which involves reflex activities in the oral and pharyngeal cavities; the transport phase, which involves moving the swallowed food bolus through the esophagus into the stomach (3). Anatomically, swallowing has been divided into three phases: oral, pharyngeal, and esophageal. The oral phase includes preparatory and early transfer phases.

Dysphagia is defined as a difficulty to swallow liquids and/or solids (4). It is classified as oropharyngeal

or esophageal, depending on where it occurs. In oropharyngeal dysphagia, symptoms arise from the dysfunctional transfer of a food bolus in the pharynx past the upper esophageal sphincter into the esophagus. Esophageal dysphagia is caused by disordered peristaltic motility or conditions that obstruct the flow of a food bolus through the esophagus into the stomach. Dysphagia may be caused by physiological changes in the mechanism of oropharyngeal or esophageal swallowing of healthy older adults (Presbyphagia) or by pathological factors of various origins (neurological, muscular, neoplastic, etc.). Oropharyngeal dysphagia is most common in older and institutionalized subjects, especially if there are additional stressors such as acute illnesses or certain medications (5). Literature data show that swallowing difficulties are present in approximately 13% of the general older population and in more than 50% of institutionalized seniors (6). Oropharyngeal dysphagia occurs most often in people with neurologic conditions or skeletal muscular disorders. Thirty percent of older patients develop dysphagia following a stroke and of those, 10 to 30% have permanent symptoms (7). Approximately 60-80% of people with neurodegenerative

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Table 1
Quality of Life and Functional Health Status Questionnaires for Oropharyngeal Dysphagia included in the review

| Authors | Questionnaire | Acronym | Inclusion | Exclusion/main characteristics of questionnaire |
|--|--|---------------------|---|--|
| A. Y. Chen, R. Frankowshi, J. Bishop-Leone et al, 2002 (16) | MD Anderson Dysphagia Inventory | MDADI | Mainly oropharyngeal dysphagia related QoL | |
| K. L. Wallace, S. Middleton, and I. J. Cook, 2000 (17) | Self-report Symptom Inventory | none | Mainly oropharyngeal dysphagia related FHS | |
| McHorney CA, Robbins J, Lomax K, Rosenbek JC, Chignell K, Kramer AE, et al., 2002 (18) | Supraesophageal Reflux Questionnaire, the SWAL QOL, SWAL CARE | SWAL QOL, SWAL CARE | Mainly oropharyngeal dysphagia related QoL | |
| A. K. Silbergleit, L. Schultz, B. H. Jacobson, T. Beardsley, and A. F. Johnson, 2012 (19) | Dysphagia Handicap Index | DHI | Combination of oropharyngeal dysphagia related HR-QoL and FHS | |
| P. C. Belafsky, D. A. Mouadeb, C. J. Rees et al., 2008 (20) | Eating Assessment Tool | EAT 10 | Mainly oropharyngeal dysphagia related FHS | |
| R. Govender, M. T. Lee, T. C. Davies et al., 2012 (21) | Swallowing Outcome After Laryngectomy | SOAL | Mainly oropharyngeal dysphagia related FHS | |
| R. Bergamaschi, P. Crivelli, C. Rezzani et al., 2008 (22) | Dysphagia in Multiple Sclerosis Questionnaire | DYMUS | Mainly oropharyngeal dysphagia related FHS | |
| R. C. Dwivedi, S. S. Rose, J. W. G. Roe et al., 2010 (23) | Sidney Swallow Questionnaire | SSQ | Mainly oropharyngeal dysphagia related FHS | |
| Kei Kawashima, Yutaka Motohashi, Ichiro Fujishima, 2004 (24) | Dysphagia Screening Questionnaire | none | Mainly oropharyngeal dysphagia related FHS | |
| V. Woisard, M. P. Andrieux, and M. Puech, 2007 (25) | Deglutition Hendicap Index | DHI | | Combination of oropharyngeal dysphagia related HR-QoL and FHS in French |
| N. Colodny, 2008 (26) | Caregiver mealtime and Dysphagia Questionnaire | CMDQ | | Target population caregivers |
| J. T. Cohen and Y. Manor, 2011 (27) | Swallowing Disturbance Questionnaire | SDQ | | Mainly oropharyngeal dysphagia related FHS in Hebrew |
| S. Martin, I. Catarina, E. Therese, and O. Claes, 2012 (28) | Dysphagia Short Questionnaire | DSQ | | Mainly oropharyngeal dysphagia related FHS in Swedish |
| A. B. M. Grudell, J. A. Alexander, F. B. Enders et al, 2007 (29) | Mayo Dysphagia Questionnaire-30 | MDQ-30 | | Measurement of a spectrum of esophageal dysphagia attributes in a population with reflux esophagitis and/or reflux peptic stricture |
| Belafsky P. C, Postma G. N., Koufman J. A., 2002 (30) | Reflux Symptom index | RSI | | Instrument assessing symptom severity in laryngopharyngeal reflux |
| Dauer E, Thompson D, Zinsmeister A R et al., 2006 (31) | Supraesophageal Reflux Questionnaire | SER | | Instrument assessing supraesophageal manifestations of reflux |
| Eypasch E, Williams J I, Wood-Dauphinee S et al. 1995 (32) | Gastrointestinal Quality of Life Index | GIQLI | | Instrument assessing QoL of patients with gastrointestinal disease |
| Locke G R, Talley N J, Weaver A L, Zinsmeister A R., 1994 (33) | Gastroesophageal Reflux Questionnaire | none | | Instrument assessing gastroesophageal reflux disease |
| Weymuller E.A., Alsarraf R., Yueh B. Et al, 2001 (34) | University of Washington Revised Quality of Life Instruments | UW-QOL-R | | Instrument assessing QoL of patients with head and neck cancer |
| Slade GD, Spencer AJ., 1994 (35) | Oral health impact | OHIP 14 | | Assessing the functional and psychosocial impacts of oral disorders |
| Pace-Balzan A, Cawood JI, Howell R, Lowe D, Rogers SN., 2004 (36) | Liverpool Oral Rehabilitation Questionnaire | LORQ3 | | Health-related QoL instrument assessing the impact of oral rehabilitation on patients' health-related quality of life (HRQOL) following treatment for oral cancer |
| J.M. Blazeby, T. Conroy, A. Bottomley et al on behalf of the European Organisation for Research and Treatment of Cancer, 2004 (37) | The European Organisation for Research and Treatment of Cancer (EORTC)QLQ-STO 22 | EORTC QLQ-STO 22 | | Health related QoL for the assessment of the quality of life in patients with gastric cancer undergoing surgery, surgery and chemoradiotherapy, palliative chemotherapy, palliative surgery and best supportive care |
| Kristin Bjordal, Eva Hammerlid, Marianne Ahlner-Elmqvist et al., 1999 (38) | the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ)-H&N35 | EORTC QLQ-H&N3 | | Assessment of the quality of life of head and neck (H&N) cancer patients in conjunction with the cancer-specific EORTC QLQ-C30 |

Table 2
 Characteristics of Quality of Life and Functional Health Status Questionnaires of Oropharyngeal Dysphagia

| Questionnaire | What it assesses/Domain | N. items | Target population | Feasibility |
|--|---|-------------------------------|--|--|
| MD Anderson Dysphagia Inventory (MDADI) | Impact of treatment of head and neck cancer on swallowing, impact of swallowing difficulty on patient's QoL | 20 | Patients with head and neck cancer | Completing the questionnaire doesn't require much time, but scoring is complicated |
| Self-report Symptom Inventory | Dysphagia FHS | 19 (prototype), 17 (modified) | Patients with oropharyngeal Dysphagia | Short and comprehensive |
| Supraesophageal Reflux Questionnaire (SWAL QOL, SWAL CARE) | Oropharyngeal dysphagia QoL, Q of care and patient satisfaction | 58 (44+14) | Patients with oropharyngeal dysphagia of different etiologies | Time consuming (at least 20 min), it has the best psychometric properties among Dysphagia HR QoL questionnaires |
| Dysphagia Handicap Index (DHI) | Dysphagia HR-QoL and FHS | 25 (7+9+9) | Patients with dysphagia | Easy and not time consuming; the most simple among dysphagia HR QoL questionnaires, good psychometric properties |
| Eating Assessment Tool (EAT 10) | Dysphagia FHS and HR-QoL; severity of oropharyngeal dysphagia | 10 | Patients with oropharyngeal dysphagia | Short and comprehensive |
| Swallowing Outcome After Laryngectomy (SOAL) | Dysphagia FHS , swallowing function | 17 | Patients with oropharyngeal dysphagia after total laryngectomy | Short and comprehensive |
| Dysphagia in Multiple Sclerosis Questionnaire (DYMUS) | Mainly oropharyngeal dysphagia related FHS | 10 | Dysphagic patients with MS | Short and comprehensive |
| Sidney Swallow Questionnaire (SSQ) | Mainly oropharyngeal dysphagia FHS | 17 | Patients with head and neck cancer | Only 87% of patients have completed the items/ questionnaire |
| Dysphagia Screening Questionnaire | Mainly oropharyngeal dysphagia in community dwelling older adults (QoL) | 15 | Autonomous older adults | Short and comprehensive |

diseases also develop dysphagia.

Oropharyngeal dysphagia negatively impacts patients' quality of life and can lead to increased risk of malnutrition, dehydration, aspiration pneumonia and death (8-10). It is therefore essential to diagnose dysphagia, in a timely fashion, in order to implement appropriate treatment and to avoid the onset of complications (11).

Dysphagia assessment in older adults relies on the same modalities as in other age groups: taking a clinical history, assessment and instrumental examinations with videofluoroscopy (VFS) and fiberoptic endoscopic evaluation of swallowing (FEES), which are considered the gold standards to determine specific swallowing impairments, patient compensation and the response to rehabilitation (12-15). However, given that symptoms of oropharyngeal dysphagia are quite specific - choking or coughing at mealtime, pain on swallowing and nasal regurgitation - numerous patient self-administered questionnaires have been developed over the last few decades to measure their health-related quality of life (HR-QoL) and functional health status (FHS). These questionnaires are used to assess oropharyngeal dysphagia and its severity, as well as to measure the impact of dysphagia and of therapeutic and rehabilitative interventions on the social, psychological and functional aspects of a patient. Since questionnaires are non-invasive diagnostic tools, are easy to understand and quick to perform, their use for older patients should be encouraged.

The purpose of this review is to provide an overview of available HR-QoL and FHS questionnaires, with indications on their target populations, their feasibility and the domains they assess, as well as their psychometric properties. A list of self-administered questionnaires containing items to evaluate dysphagia, which are not specific to oropharyngeal dysphagia, is also provided.

Materials and methods

This review is based on a qualitative analysis of articles cited in Pubmed. A defined search strategy was applied, with specific keywords for dysphagia tests (self-assessment, functional impairment, quality of life, dysphagia symptoms, older adults). The review was restricted to observational studies with adult populations with dysphagia published from 1990 to June 2014. Reference lists of all included articles were searched for additional literature. Information about self-assessment questionnaires was extracted from eligible studies. The examination of self assessment tools was limited to articles published in English and Italian. The target populations, the feasibility and the domains that were assessed by each questionnaire are provided. Information on the psychometric properties of questionnaires provided by authors and some reviews are presented.

Results

A total of 23 self-assessment questionnaires on Health-related Quality of Life and Functional Health status

for different populations were identified. Fourteen questionnaires were excluded from the analysis for the following reasons: the questionnaire was written in a language other than English or Italian (n=3); the questionnaire was specific for caregivers of dysphagic patients (n=1); the questionnaires were not specific for oropharyngeal dysphagia (n=10). Nine questionnaires found in articles published in English and/or Italian and validated in adult populations with different pathologies were examined (Table 1).

Questionnaires on functional health status and quality of life of patients with oropharyngeal dysphagia

Characteristics of the target populations and the feasibility of self assessment questionnaires for oropharyngeal dysphagia are summarized in Table 2.

MD Anderson dysphagia inventory (MDADI)

MD Anderson dysphagia inventory (MDADI) is a self assessment questionnaire composed of 20 items designed to evaluate the impact of dysphagia on the quality of life of patients with head and neck cancer, who are undergoing surgery and chemo-radiotherapy (A. Y. Chen, R. Frankowshi, J. Bishop-Leone et al, 2002). The items assess four aspects of quality of life: emotional, physical, functional and overall conditions. Only four items explicitly investigate the presence of dysphagia throughout the analyses of physiological aspects: "It takes me longer to eat because of my swallowing problem", "I cough when I try to drink liquids", "I limit my food intake because of my swallowing difficulty", "I cannot maintain my weight because of my swallowing problem". This study involved 100 patients with head and neck cancer, while the reproducibility was evaluated in a sample of 29 patients. Construct validity was determined by comparing the results of the MDADI questionnaire with the SF-36, while the criterion validity was tested with the Performance Status Scale. Completing the questionnaire does not require much time, but scoring is complicated. The authors reported good internal consistency (Cronbach α varies between 0.85 and 0.93) and discrete validity and reproducibility (Cronbach $\alpha=0.69$ for the global scale; Cronbach $\alpha=0.88$ for the emotional and functional scales; Cronbach $\alpha=0.86$ for the physical scale) of MDADI.

Self-Report symptom questionnaire

The Prototype Self-report Symptom Inventory (19 items) proposed by Wallace at (K. L. Wallace, S. Middleton, and I. J. Cook, 2000), gave rise to the Modified Self-report Inventory (17 items). The Modified Self-report Inventory was derived from a cross sectional study of a sample of 45 patients with oropharyngeal

dysphagia of neuromyogenic etiology, 11 patients with oropharyngeal dysphagia caused by Zenker's diverticulum and 19 nondysphagic controls. According to the authors, the 17 question inventory shows strong test-retest reliability over 2 weeks as well as face, content and construct validity, but its responsiveness to treatment in neuromyogenic dysphagia was not defined.

SWAL-QOL/SWAL-CARE

SWAL-QOL/SWAL-CARE is a self-assessment questionnaire which was administered to 386 patients with oropharyngeal dysphagia of different etiologies (vascular, neurodegenerative, neoplastic, traumatic) (McHorney CA, Robbins J, Lomax K, Rosenbek JC, Chignell K, Kramer AE, et al., 2002). It consists of two parts. The first part, SWAL-QOL, is composed of 44 items which assess the impact of dysphagia on quality of life. There are also 14 questions that investigate the presence of specific signs of dysphagia such as tracheobronchial aspiration and laryngeal penetration. The second part, SWAL-CARE, comprises 15 items which examine the effectiveness of a therapeutic intervention. This questionnaire was validated against video fluoroscopy. It is very long and its compilation is time consuming (it takes at least 20 minutes). These characteristics could negatively affect patients' compliance. The authors reported very good internal consistency (Cronbach α between 0.80 and 0.95) and reproducibility (Cronbach $\alpha=0.60-0.91$).

Deglutition handicap index

This questionnaire, based on the Voice Handicap Index, is composed of 3 groups of 10 items each (A. K. Silbergleit, L. Schultz, B. H. Jacobson, T. Beardsley, and A. F. Johnson, 2012). The first group of questions assesses physical signs of swallowing difficulties, the second group evaluates the functional status of patients (nutritional status and eventual pulmonary complications, such as aspiration pneumonia), the third part appraises emotional aspects and QoL. The construct validity of the first part of the questionnaire was tested with videofluoroscopy. The validity of items concerning functional aspects was tested against data on the nutritional status of patients. For emotional aspects, patients' quality of life was assessed. The authors found good construct and content validity and very good internal consistency and reproducibility.

Eating assessment Tool (EAT-10)

Eating assessment Tool (EAT-10) is a self-assessment questionnaire designed by Belafsky (P. C. Belafsky, D. A. Mouadeb, C. J. Rees et al., 2008). The validation of the original questionnaire in English involved a total of 235 subjects; 21% of patients had oropharyngeal dysphagia,

11% displayed esophageal dysphagia, 22% suffered from phonatory disorders, 18% had head and neck cancer and 28% experienced gastroesophageal reflux. The questionnaire is validated in different languages (39). It consists of 10 items. Two items (items n. 2 and n. 7) assess the impact of dysphagia on patients' quality of life; all other specifically investigate the presence and severity of dysphagia. The brevity of EAT 10 makes it simple and quick to complete (approximately 2 minutes). It has very good internal consistency (Cronbach $\alpha=0.96$) and good reproducibility, which, however, was evaluated only in the group of patients with esophageal dysphagia.

Swallowing outcome after laryngectomy (SOAL)

To develop this questionnaire, a cross sectional study was performed on a relatively small group of volunteer laryngectomees from the UK (n=19) (mean 5 years post-surgery), 19 dysphagic and 20 non-dysphagic patients (R. Govender, M. T. Lee, T. C. Davies et al., 2012). The questionnaire is composed of 17 items. Only two items: "Has your enjoyment of food reduced?" and "Do you feel self-conscious eating with other people?" assess patients' QoL. All other items measure oropharyngeal dysphagia-related functional health status. Responses from the dysphagic group were confronted with the results of the modified barium swallow examination and a strong positive correlation was found with the subjective SOAL score ($r=0.5$; $p=0.03$). According to the authors, the questionnaire has excellent internal consistency (Cronbach $\alpha=0.91$ for laryngectomees; Cronbach $\alpha=0.96$ for all groups together).

Sidney swallow questionnaire (SSQ)

Sidney swallow questionnaire (SSQ) published by Dwivedi et al in 2010, is identical to the Modified Self-report inventory of Wallace et al (R. C. Dwivedi, S. S. Rose, J. W. G. Roe et al. , 2010). It is a 17 item questionnaire that was administered to 62 patients with head and neck cancer during a follow up period. Terminal phase patients, and those with other malignancies or diagnoses of neuromuscular diseases, were excluded from the study. All items investigate, specifically, the presence of oropharyngeal dysphagia, with foods of different texture, difficulties to start the swallowing process, reduced oral and pharyngeal clearance and signs of tracheobroncheal aspiration. Only the last item - "How much does your swallowing problem interfere with your enjoyment or quality of life?" - investigates the impact of swallowing deficiencies on patients' quality of life. This questionnaire was validated with MDADI, which the authors considered a gold standard among self administered questionnaires. The authors reported excellent internal consistency

(Cronbach $\alpha=0.95$) and good reproducibility, calculated with Spearman's correlation coefficient (0.71-0.83). Eighty-seven percent of the patients completed the questionnaire.

Dysphagia in multiple sclerosis (DYMUS)

Dysphagia in multiple sclerosis (DYMUS) is the first specific questionnaire to precociously identify dysphagia in patients with multiple sclerosis (MS) (R. Bergamaschi, P. Crivelli, C. Rezzani et al., 2008). It comprises 15 items exclusively evaluating signs of dysphagia and patients' functional status. It was administered to 226 consecutive MS patients. According to the authors, DYMUS showed very good internal consistency (Cronbach $\alpha=0.88$ for all questions; Cronbach $\alpha=0.85$ for solids; Cronbach $\alpha=0.87$ for liquids).

Dysphagia screening questionnaire

Dysphagia screening questionnaire consists of 14 items, and it was used in a cross sectional study on 1313 older adults living at home, to determine the prevalence of dysphagia and to clarify the relation between dysphagia and the level of daily living competence (Kei Kawashima, Yutaka Motohashi, Ichiro Fujishima, 2004). The questionnaire showed good internal consistency (Cronbach $\alpha=0.83$). It evaluates six factors: past history of pneumonia, nutritional status, and pharyngeal, oral, esophageal and airway protective functions.

Discussion

This review provides information on currently available questionnaires for the self assessment of both HR-QoL and FHS in oropharyngeal dysphagia and a brief overview of questionnaires containing items to evaluate dysphagia, but focusing on other primary diseases associated with dysphagia.

According to the authors, all the self assessment questionnaires for oropharyngeal dysphagia showed satisfactory psychometric properties. In contrast to this, two recent reviews, one on HR-QoL (Timmerman AA et al, 2014) and another on FHS questionnaires (Speyer R et al, 2014), presented quite different results. Those two reviews analyzed the psychometric properties of the majority of the questionnaires for oropharyngeal dysphagia shown in Table 2 (MDADI, DHI, SWAL-QOL, EAT-10, SOAL, Self reported inventory and SSQ) using the COSMIN checklist and the 4-point rating scale according to Terwee et al. (40, 41). The methodological quality of each questionnaire, was evaluated for internal consistency, reliability, measurement error, content, construct and criterion validity and responsiveness. According to the Health-related Quality of Life review, only the DHI and SWAL-QOL questionnaires showed

strong properties, especially for all validity aspects and the interpretability of the questionnaires (42). The SWAL-QOL homogeneously measures what it claims to, in an appropriate target population of patients with dysphagia. It differentiates relevant clinical characteristics such as normal swallowing, the manner of food intake, food texture, liquid consistency and symptom severity. Shortcomings were found in its reproducibility and floor and ceiling effects for the score ranges (over and under estimating). The DHI received positive ratings on almost all validity aspects and on the ability to distinguish between patients at one point, but its face validity was questionable. Regarding the review of psychometric characteristics of Functional Health Status, all the questionnaires analyzed (EAT-10, SOAL, Self reported inventory and SSQ) had poor overall methodological quality scores (43). The latter was due to very small samples of patients used to validate the questionnaires, inaccurate evaluation of all psychometric properties and inappropriate tests used for the analyses.

Conclusion

The availability of valid questionnaires is very important in daily clinical practice to facilitate early diagnosis of dysphagia and to assess the impact of therapies on patients' quality of life. The use of non-invasive, self administered questionnaires is even more crucial for geriatric patients who have developed dysphagia and are too frail to undergo some invasive instrumental examinations.

Given that numerous self administered HR-QoL and FHS questionnaires for oropharyngeal dysphagia are already available, but their measurement properties and their methodological characteristics are not always robust, the first step should be to improve the characteristics of these existing tools. Secondly, given that the self assessment of oropharyngeal dysphagia is particularly important in geriatric settings, developing specific questionnaires for older adults, and caregivers who assist them, could play a critical role in the precocious recognition of dysphagia.

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