A systematic review of self-reported swallowing assessments in progressive neurological disorders

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Abstract

Introduction: Dysphagia experienced as a consequence of neurodegenerative disease can have severe consequences on a patient's health and well-being. Regular assessment of swallowing function can assist to achieve adequate nutrition and hydration. Here we review subjective swallowing assessments currently available are suitable for use in people with neurodegenerative disease. Measurement properties were reviewed for each tool and coverage of the World Health Organization's International Classification of Functioning, Disability and Health (WHO ICF) was considered.

Methods: Assessments were identified following a review of the published literature Instruments were reviewed on the basis of reliability and validity, as well as administrative properties, such an interpretability, acceptability, and feasibility. Tools were also evaluated according to the WHO ICF framework.

Results: In total, 19 studies were identified for full-text review from 13,315 abstracts. Nine self-reported dysphagia assessment tools suitable for use in progressive neurological disorders were identified. The Swallowing Quality of Life Questionnaire (SWAL-QOL) yields the strongest combination of reliability (including internal consistency and test-retest reliability) and convergent validity while simultaneously covering all WHO ICF domains. Lengthy administration time was identified as a limitation of the SWAL-QOL.

Conclusions: The review highlights a relative lack of well validated self-report questionnaires in dysphagia for people with progressive neurological disease. Additional validation and evaluation of the clinical utility of the tools currently available is required to further promote an informed selection of available assessments.

Keywords: deglutition, deglutition disorders; dysphagia, assessment, subjective, quality of life, questionnaire, progressive neurological, neurodegenerative

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Introduction

Dysphagia is an expected symptom of neurodegenerative disease. Common symptoms of dysphagia include coughing or choking, reduced mastication, difficulty controlling solids or liquids in the mouth, drooling, nasal regurgitation, food lodging in the pharynx, and aspiration (matter entering the lungs). In the case of neurodegenerative conditions, these symptoms may be exacerbated by co-existing changes to motor control, making it difficult to manipulate cutlery and feed independently. People with dysphagia are at risk of malnutrition, dehydration, and pneumonia secondary to aspiration (Threats, 2007), which is the leading cause of death in people with multiple sclerosis (MS) (Adams, 1989) and Parkinson's disease (PD) (Hely, Reid, Adena, Halliday, & Morris, 2008). Dysphagia also has associated social and psychological consequences that affect overall quality of life (QOL), including reduced mental health, self-esteem, and social isolation (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002). The prevalence of dysphagia in neurodegenerative diseases is high, with 20-80% of people with PD (Volonté, Porta, & Comi, 2002; Coates & Bakheit, 1997) and over 30% of those with MS (Prosiegel, Schelling, & Wagner-Sonntag, 2004) experiencing swallowing impairment. Despite being highly prevalent, dysphagia is chronically under-reported in neurodegenerative populations with initial diagnosis often occurring with an episode of aspiration pneumonia (Manor, Giladi, Cohen, Fliss, & Cohen, 2007).

Identifying dysphagia in the early stages of a progressive neurological disorder can assist in implementing preventative measures, reduce the risk of complications, and assist in achieving optimal health and QOL outcomes (Bergamaschi et al., 2008). There are often complex social and psychological dynamics associated with neurodegenerative conditions that must be considered in the assessment process. The World Health Organization's International Classification of Functioning, Disability, and Health (WHO ICF) (2001) provides a multifaceted framework for health by considering disability at the level of body functions and structures, potential activity undertaken by the individual, and participation in everyday life (Power, Anderson, & Togher, 2011). The framework is important in the consideration of outcome measures to ensure a holistic approach to assessment. Traditionally, swallowing assessment consists of a clinical bedside assessment and instrumental analysis if indicated, including Videofluoroscopic Study of Swallowing (VFSS) and Fibreoptic Endoscopic Evaluation of Swallowing (FEES).The typical bedside evaluation of swallowing is clinical and methodical in nature, with emphasis on the physiological consequences of swallowing impairment. Assessment is usually performed in a medical setting, with little talking, and the patient is required to eat food that they may not consider appealing. The Speech Language Pathologist will then provide an objective assessment report. Threats (2007) compares this clinical setting with a more natural and social setting, where there is often talking when eating and drinking and the food available is likely to be more appealing than that offered in the clinical setting. The experience and therefore the performance of eating and drinking are markedly different between these two settings (Threats, 2007). Instrumental analysis is used to facilitate a further understanding of the physiological and mechanical aspects of swallowing in order to develop an overall impression of dysphagia severity. Although considered the gold standard of dysphagia assessment (Evatt et al. 2009), instrumental analysis is a poor measure of overall functional disability, and forming recommendations on the basis of the results of instrumental analysis alone may lead to a management approach that has little practicality to the patient (Threats, 2007). A qualitative, patient-centered assessment tool allows for reliable evaluation of the psychosocial burden often associated with dysphagia, as well as overall impact on QOL (Belafsky et al., 2008, Wallace, Middleton, & Cook, 2000). Self-reported assessments can be completed autonomously away from the clinical setting and results can identify patients in need of more invasive instrumental assessment (Cohen & Manor, 2011).

Despite their advantages, self-reported swallowing assessments are not routinely adopted into clinical practice. This may be reflective of the lack of recognition of dysphagia in people with neurodegenerative disease, that no one tool has been identified as preferable for use in these populations. This study presents an evaluation of the psychometric and administrative properties of self-reported swallowing assessments found in the literature and suitable for use in neurodegenerative disorders. The relevance of each tool to the WHO ICF framework was also assessed.

Methods

Searches were conducted using the Medline, CINAHL, and ScienceDirect databases, for the years 1990 to October, 2013. The following keywords were used: *dysphagia* or *deglutition disorder** or *swallowing disorder** and *questionnaire* or *assessment* or *survey* and *progressive neurological* or *multiple sclerosis* or *Parkinson's disease* and *quality of life*. A further search was conducted via the Google search engine to ensure all assessments in the public domain were retrieved. All possible combinations of the terms *subjective, self-reported, dysphagia, swallowing disorder*, deglution disorder*, questionnaire, assessment,* and *survey* were used, and the first 10 pages of search results scanned. Two authors (MK and AV) independently screened the relevant titles to exclude papers that were obviously irrelevant then evaluated the abstracts to determine eligibility for full text review. The reference lists of selected articles were also searched to identify additional papers for inclusion in this review. In the event of disagreement over inclusion of a particular paper, all listed authors formed a consensus by reassessing the inclusion criteria. The search was not restricted to English language papers

Types of studies:

Papers were included for full text review if they contained information on the development or validation of subjective or self-reported dysphagia questionnaires or assessments. Assessment tools were included in the review if they were used in neurodegenerative disease populations.

Types of study participants:

Participants included were of any age, sex, ethnicity, and stage of illness. Studies were only included if their participants had a genetically or clinically confirmed diagnosis of a progressive neurological disorder.

Outcome measures:

Identified tools were assessed according to reliability and validity, as well as administrative properties, such as interpretability, acceptability, and feasibility (refer to Table I – Evaluation criteria for assessment tools). Assessment tools were also assessed in regards to their relevance to the WHO ICF.

Table I - Evaluation criteria for assessment tools

Criterion	**Definition**
Appropriateness	Is the content of the instrument appropriate to the questions which the study is intended to address?
Reliability	Does the instrument produce results that are reproducible and internally consistent?
Validity	Does the instrument measure what it claims to measure?

Responsiveness	Does the instrument detect changes over time that matter to patients?
Precision	How precise are the scores of the instrument?
Interpretability	Are the results of the assessment meaningful?
Acceptability	Is the instrument acceptable to patients, or does it impose a level of burden?

Fitzpatrick et al., 1998

Results

A total of 13,315 papers were identified from the database searches after duplicates were removed. Two authors (MK and AV) screened the abstracts of these papers and excluded those that were obviously irrelevant. Papers were primarily excluded for focusing on dysphagia secondary to different etiologies (for example, stroke, gastroeosophageal reflux disease, chronic obstructive pulmonary disease, cervical spine surgery, laryngectomy, or head and neck cancer). In total, 19 papers were included for full text review based on our inclusion criteria. No further papers were identified following a search of the reference lists of the papers identified for a full text analysis. A search was conducted using the Google search tool, however no further papers were identified as appropriate for inclusion in this review (refer to Figure 1). In total, nine subjective swallowing assessments evaluated in neurodegenerative populations were identified in the literature. All of the assessments had information regarding psychometric evaluation. Features of each screening tool (listed alphabetically) are described in Table II. Measurement and administrative characteristics of each tool (reliability, validity, and sensitivity/specificity) are summarised in Table III. Table IV shows each individual assessment's relevance to the WHO ICF framework. Appendix 1 contains a more detailed analysis of each assessment and its individual items in compliance with the WHO ICF.

Figure 1 – Flow chart of systematic review process

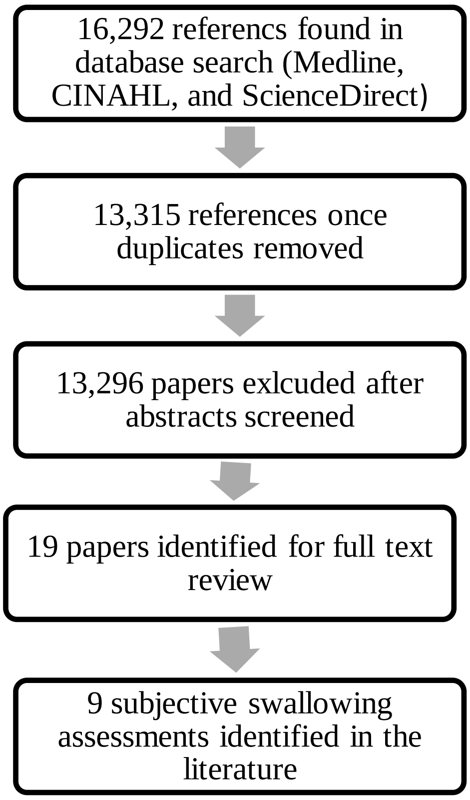

Table II – Summary of assessment tools (in alphabetical order)

Screening Tool	**Number of items**	**Areas of assessment/subscales**	**Administration Time**
Dysphagia in Multiple Sclerosis Questionnaire (DYMUS) (Bergamaschi et al., 2008)	10	• Dysphagia to solids – 7 items • Dysphagia to liquids – 3 items	Not specified
Dysphapark questionnaire (Bayés-Rusiñol et al., 2011)	18	• Swallowing efficiency – 9 items • Swallowing safety – 9 items	Not specified
Eating Assessment Tool (EAT-10) (Belafsky et al., 2008)	10	• Loss of weight - 1 item • Interference with ability to go out for meals – 1 item • Dysphagia (increased effort) to liquids – 1 item • Dysphagia (increased effort and food sticking in throat) to solids – 2 items	Less than 2 minutes

		- Dysphagia (increased effort) to pills – 1 item - Presence of odynophagia (pain on swallowing) – 1 item - Effect of dysphagia on eating pleasure - 1 item - Coughing when eating - 1 item - Stress related to swallowing - 1 item	
Radboud Oral Motor Inventory for Parkinson's Disease (ROMP) (Kalf et al., 2011)	23	- Speech function – 7 items - Swallowing - 7 items 1. Frequency of choking when eating and drinking 2. Limitations during drinking 3. Limitations during eating 4. Difficulty swallowing pills 5. Limitations dining with others 6. Concerns regarding difficulty swallowing 7. Feeling of bother as a result of difficulty	Not specified

		swallowing • Saliva control - 9 items	
Swallowing Disturbance Questionnaire (SDQ) (Cohen & Manor, 2011)	15	• Oral phase of swallowing – 5 items • Pharyngeal phase of swallowing - 10 items	10 minutes
SWAL-QOL (McHorney et al., 2000)	44	Items cover 10 Quality of Life (QOL) concepts: • Food selection – 2 items • Burden – 2 items • Mental health – 5 items • Social functioning – 5 items • Fear – 4 items • Eating duration – 2 items • Eating desire – 3 items • Communication – 2 items • Sleep – 2 items • Fatigue – 3 items	15 minutes

		Also included is a symptom frequency scale - 14 items that is added to the score of the above items to calculate the final total.	
Sydney Swallow Questionnaire (SSQ) (Wallace et al., 2000)	17	Three main variables: • Anatomic region, including oral cavity, glottis, and pharynx • Type of dysfunction • Swallowed bolus consistency	5-10 minutes
The Deglutition Handicap Index **(**Woisard, Andrieux, & Puech, 2006)	30	• Physical (symptoms) - 10 items • Functional (nutritional and respiratory consequences) – 10 items • Emotional (psychological consequences) – 10 items	Not specified
The Dysphagia Handicap Index (DHI) (Silbergleit, Shulz, Jacobson, Beardsley,	25	Three subscales: • Physical scale - 9 items	Not specified

& Johnson, 2012)		• Emotional scale - 7 items • Functional scale - 9 items	

Dysphagia in Multiple Sclerosis (DYMUS) Questionnaire (Bergamaschi et al., 2008)

The Dysphagia in Multiple Sclerosis Questionnaire (DYMUS) was designed as a screening tool for dysphagia in the early stages of the disease. The DYMUS primarily aims to identify patients in need of further assessment in order to reduce the potential health and social consequences of dysphagia in MS. The DYMUS assesses dysphagia to solids and dysphagia to liquids, with each item answered dichotomously, either positive (1) or negative (0) depending on the presence or absence of a dysphagic event (Bergamaschi et al., 2008). The DYMUS was validated in a cohort of 1734 patients across 13 MS specific centers, with 31% (n=541) recording at least one abnormal response.

The DYMUS primarily addresses the Body Functions component of the WHO ICF (see Table IV). Nine items on the DYMUS assess for difficulty chewing particular types of food, weight loss, globus post swallow, coughing and choking with oral intake, and requiring multiple sips or swallowing to clear a bolus. The remaining item on the DYMUS relates to activity limitation (cutting food into small pieces before swallowing).

Advantages - DYMUS

The DYMUS is currently the only validated MS-specific subjective dysphagia questionnaire (Bergamaschi et al., 2008). At only 10 items in length, the DYMUS is brief to administer and interpret, reducing clinical burden. As the DYMUS is divided into two subscales, it can be used to assess dysphagia to solids or liquids independently, which can assist in guiding dysphagia management (González-Fernández & Daniels, 2008). The reliability and homogeneity of the DYMUS (Cronbach's alpha 0.91, where > 0.70 is considered good) is excellent (Bergamaschi et al., 2009) making the DYMUS a consistent tool to include in the dysphagia assessment battery.

Limitations -DYMUS

The DYMUS focuses on the physiological implications of dysphagia, with the main aim of aspiration prevention (Bergamaschi et al., 2008). It is therefore a limited indicator of social and psychological impact of dysphagia. Given the DYMUS is validated solely in the MS population, use in other neurodegenerative conditions requires further independent validation.

Dysphapark Questionnaire (DQ) (Bayés-Rusiñol et al., 2011)

The Dysphapark Questionnaire (DQ) was developed to assess the level of awareness of dysphagia in the PD population. The DQ contains 18 items divided into two subscales – swallowing efficiency (9 items) and swallowing safety (9 items). Each item relates to a specific swallowing-related event and is scored from 0 to 3, where 0 = never, 1 = sometimes, 2 = often, and 3 = always. To validate the DQ, the authors sent 2,000 copies to PD patients from 27 Spanish provinces. Patients were selected by movement disorder neurologists. From these 2,000 questionnaires, 470 were returned to the authorship group via post (23.5%). Ninety percent of these participants were found to have problems of efficacy and safety of swallowing whilst 79.45% were not aware of having dysphagia.

The DQ predominantly addresses body function and structures of the WHO ICF, focusing on physiological breakdown of the swallowing process.

Advantages– Dysphapark Questionnaire

The DQ is short and does not contain subscales or visual scales that require the calculation of a raw score, adding to its ease of use.

Limitations – Dysphapark Questionnaire

The survey was sent via mail, with little information pertaining to how patients were orientated to the survey prior to receiving it. There was a low response rate (470/2000; 23.5%). It is possible that respondents were not representative of the PD population. The DQ requires further psychometric evaluation in a broader population group in terms of age and severity of disease. The participant group consisted predominantly of patients with less severe symptoms as measured by Hoehn and Yahr scaling (Hoehn & Yahr, 1967). Most of the participant group (83.7%) were in stages I and II of the disease, with only 5.6% in stage IV-V (more severe). Comparison between questionnaire results and instrumental or electrophysiological measures of swallow would further promote the validity of the tool. Currently the DQ is only available in Spanish and requires validation in other languages.

Eating Assessment Tool (Eat-10) (Belafsky et al., 2008)

The EAT-10 was developed by a team of dysphagia experts from multiple professions, including gastroenterology, otolaryngology, speech language pathology, and nutrition. Its creation was motivated by a survey of 200 Speech Language Pathologists (SLP) in California, USA. The results of this survey indicated that self-rated swallowing questionnaires were not routinely used in clinical practice. The authors cited length of administration and scoring time as a possible explanation, as well as pre-existing questionnaires only focusing on isolated groups of dysphagia patients and therefore not appropriate for wider use. Each item on the EAT-10 is scored by the patient on a scale from 0 to 4, where 0 indicates no problem, and 4 indicates severe problem. A score ≥ 3 on any individual item is considered abnormal and indicative of dysphagia (Belafsky et al., 2008). The EAT-10 was validated in a cohort of 235 individuals, 21% (n=50) of whom presented with oropharyngeal dysphagia of neurological origin, including stroke, PD, amyotrophic lateral sclerosis, or pseudobulbar palsy.

The EAT-10 predominantly addresses body function and structures of the WHO ICF, focusing on physiological breakdown of the swallowing process. Two items relate to possible impact on activity; ‘The pleasure of eating is affected by my swallowing’, and ‘Swallowing is stressful’. Only one item assesses the impact on participation (‘my swallowing problem interferes with my ability to go out for meals’) (see Table IV).

Advantages– Eat-10

The EAT-10 is quick to administer at less than two minutes (Belafsky et al., 2008). In a comparison of swallowing-specific questionnaires, the EAT-10 was found to be more easily read and understood than others (Zraick, Atcherson, & Ham, 2012), supporting its use in progressive neurological populations with associated cognitive decline. The EAT-

10 does not contain subscales or visual scales that require the calculation of a raw score, further adding to its ease of use. The probe statements are designed to be symptom-specific to the oral and pharyngeal phases of swallowing. The psychometric properties of the EAT-10 indicate good test-retest reproducibility (refer to Table II), making its use advantageous in everyday clinical practice (Belafsky et al., 2008).

Limitations – EAT-10

The EAT-10 has not been evaluated in longitudinal studies and therefore its effectiveness in the measurement of dysphagia progression over time is unknown. The EAT-10 focuses on the physiological implications of dysphagia, and does not address possible social, emotional, and functional impacts. The authors argue this omission is offset by the test's simplicity, ease of use, ease of scoring, and application to dysphagic patients of varying causes. The authors of the EAT-10 acknowledge the need for further validation across age, race, and socioeconomic groups (Belafsky et al., 2008).

Radboud Oral Motor Inventory for Parkinson's Disease (ROMP) (Kalf et al., 2011)

The Radboud Oral Motor Inventory for Parkinson's disease (ROMP) consists of three subscales: Speech, Swallowing, and Saliva control. For the purpose of this paper, only the dysphagia subscale is reviewed.

The ROMP dysphagia component was developed after a review of three already existing assessments – the Dutch version of the Swallowing Quality of Life (SWAL-QOL) questionnaire (Bogaardt, Speyer, Baijens, & Fokkens, 2009), the Performance Status

Scale for Head and Neck Cancer Patients (List, Ritter-Sterr, & Lansky, 2006), and the Swallowing Disturbance Questionnaire (SDQ) (Manor et al., 2007). Each item is scored from 1-5 (where 1 = normal and 5 = most severe). The items on the ROMP swallowing subscale probe for choking episodes during oral intake, limitations relating to drinking and eating, difficulty swallowing pills, limitations regarding dining with others, concerns regarding swallowing difficulties, and the degree of bother the patient experiences secondary to their swallowing difficulties.

The three components of the ROMP were designed to assess speech, swallowing, and saliva control issues specific to PD according to the components of the WHO ICF (see Table IV) (Kalf et al., 2011). The swallowing component alone covers items mainly referring to Body Functions and Structures. One item, 'Does your swallowing difficulty limit your dining with others?' addresses possible limitation on participation.

Advantages - ROMP

The ROMP is short in order to ease administrative and patient burden (Kalf et al., 2011). The psychometric properties of the ROMP are strong (refer to Table II), with high internal consistency. The authors controlled for any associated cognitive impairment expected in the PD population by repeating every item in the response possibility (Kalf et al., 2011).

Limitations - ROMP

The ROMP was validated on community-dwelling patients with mild to moderate symptoms, and not severe or hospitalised patients. The authors raise issues with subjectivity, in that people with PD tend to rate symptoms, such as speech intelligibility, as being less severe than their caregivers. Low patient-proxy agreement may justify the creation of a caregiver-rated version of the ROMP (Kalf et al., 2011).

Swallowing Disturbance Questionnaire (SDQ) (Cohen & Manor, 2011)

The SDQ was designed for use in the PD population, and can be completed periodically throughout the course of the disease to detect and monitor dysphagia. During development, results of the SDQ were compared with results of a clinical oral-motor examination and FEES (Cohen & Manor, 2011).

The SDQ contains 15 items covering dysphagia symptoms that appear in the oral and pharyngeal phases of swallowing. Questions 1-14 are marked on a scale ranging from 0-3 where 0 = never, 1 = seldom (once a month or less), 2 = frequently (1-7 times a week), 3 = very frequently (> 7 times a week). Question 15 is answered with a “yes” or “no”, scoring 0.5 or 2.5 respectively. A score of more than 12.3 (determined in a population of varying etiologies) indicates the likely presence of dysphagia (Cohen & Manor, 2011).

The SDQ solely addresses the body functions domain of the WHO ICF (see Table IV).

Advantages - SDQ

Originally designed specifically for PD, the SDQ has been used in dysphagic populations of different etiologies, including stroke, other neurodegenerative disease, gastrointestinal disease, and following head and neck surgery (Cohen & Manor, 2011). Responses to the SDQ items have been found to correlate with results of structural and instrumental analysis (for example, oral motor examination and FEES) (79.7% sensitivity, 73% specificity) (Cohen & Manor, 2011). The SDQ is short and although administration time is not documented in the initial development paper (Manor et al., 2007), it is estimated to take 10 minutes or less to complete (Evatt et al., 2009).

Limitations - SDQ

Individuals who participated in the SDQ validation study were referred by a SLP, and thus were likely to be presenting with a speech, voice, or swallowing impairment prior to assessment. Therefore, the SDQ scores were likely higher in the participant group than that of the general PD population (Cohen & Manor, 2011). All PD patients in the original SDQ development study were assessed in their *on* state (approximately one to two hours post anti-Parkinson's medication). This may have affected the results of the SDQ, as patients might experience swallowing disturbances only in their *off* state and, if so, an examination performed during their *on* state may fail to detect any impairment. In the original validation study, results of the SDQ were compared with a non-standardized oral motor examination, conducted and subjectively rated by a SLP. Inter-rater reliability between the SLP rating the oral motor examination was not determined.

Sydney Swallow Questionnaire (SSQ) (Wallace et al., 2000)

The Sydney Swallow Questionnaire (SSQ) was designed to measure the symptomatic severity of oropharyngeal dysphagia of various etiologies (Wallace et al., 2000). The SSQ covers three swallowing variables; 1) anatomical region (oral cavity, glottis, and pharynx); 2) type of dysfunction; and 3) swallowed bolus consistency. Within each anatomical region, the potential functional disturbances are considered. Seventeen of the 19 questions are answered by marking a 10mm horizontal visual analogue scale X' at the point which the patient feels best represents the severity of the particular dysfunction. The distance to the centre of the marked 'X' from the left-hand side of the line is measured to the nearest millimeter and converted to a score out of 100. The maximum possible score is therefore 1700, with a higher score indicating more severe impact on swallowing. Questions 12 and 13 yield single integer scores from 0-5 and 0-3 respectively, based on eating times for an "average meal" and "a scoop of ice cream". The SSQ was validated in a group of individuals with dysphagia of various etiologies (n=48). Twelve (25%) of this group presented with PD, 4 (8.3%) presented with a movement disorders (e.g. dystonia), and 6 (12.5%) presented with amyotrophic lateral sclerosis. The results from this group were compared to a global dysphagia score determined by instrumental examination and other clinical indicators. Face validity of the SSQ was determined by a poll of twenty-five experts in the field of dysphagia. Sixteen of the 19 items were deemed to be moderately to highly relevant by more than 80% of respondents, and three questions were deemed to have little relevance by 30% of respondents. These three questions related to time taken to eat a scoop of ice cream (item 13), reports of drooling (item 17), and perceived severity of the persons swallowing problem on the day of assessment (item 18). Two of these questions were subsequently removed (items 13 and 17), with item 18 remaining as it was deemed significant by factor analysis (Wallace et al., 2000). The final SSQ therefore consists of 17 items.

The SSQ focuses on the WHO ICF domain of Body Function and Structure, with 9 of the 17 items assessing issues related to the different phases of swallowing (see Table IV). One item on the SSQ addresses the overall health condition, by a subjective rating of their overall swallowing impairment. The SSQ also addresses participation, asking the patient to rate the overall interference of dysphagia on QOL. Five items on the SSQ are related to possible environmental factors that may affect swallowing, by probing for difficulty swallowing certain textures and consistencies of solids and fluids. One item on the SSQ relates to the time required to eat an average meal. Given that time allowed for a meal is often dictated by external factors, such as the clinical setting or availability of feeding assistance, this item could be considered an environmental consideration.

Advantages– SSQ

The SSQ is not disease-specific, making it an appropriate tool for use in a variety of dysphagia groups. The SSQ demonstrated a high level of reliability in detecting dysphagia without direct clinical evaluation when compared to the global dysphagia score (refer to Table II).

Limitations - SSQ

The SSQ is scored on a visual analog scale, which some argue ads burden to the scorer when compared to a dichotomous, or Likert scale (Belafsky et al., 2008). This may make the SSQ less desirable to some clinicians.

Swallowing Quality of Life (SWAL-QOL) Questionnaire (McHorney et al., 2000)

One of two patient-centered outcome tools (the other being the SWAL-CARE; a 15-item tool that assesses quality of care and patient satisfaction), the SWAL-QOL was designed to assess the physical, social, psychological, and cultural experiences associated with eating (McHorney, Martin-Harris, Robbins, & Rosenbek, 2006). The SWAL-QOL contains 44 items covering 10 quality of life domains pertaining to dysphagia. Each item is answered on a 5 point Likert scale, with different instructions to the patient for different areas of assessment. Each item is equally weighted and calculated into an overall score, with a lower score indicating a worse QOL. The SWAL-QOL was validated in a cohort of 386 participants, with 49 (12.7%) having a progressive neurological disease (McHorney et al., 2002).

The SWAL-QOL addresses multiple WHO ICF domains (see Table IV). Issues relating to the overall health condition are addressed with broad questions, such as ‘Feel weak?’, ‘Feel tired?’, ‘Feel exhausted?’, and by asking the patient to mark their overall health as poor, fair, good, very good, or excellent. The SWAL-QOL probes for issues relating to Body Function and Structure across multiple stages of swallowing (oral, pharyngeal, esophageal) by probing for coughing with oral intake, food sticking in mouth and throat, difficulty chewing, and issues with speech intelligibility and saliva management.

Psychological consequences of dysphagia, such as fear or anxiety related to eating and drinking, are also considered in the SWAL-QOL items, and can be classified as an impairment, and therefore also fall under the category of Body Function. The SWAL-QOL also probes for changes to activities and participation behaviours, including not going out to eat, restrictions on social life, reduced desire to eat, and extended mealtimes. There are no direct questions relating to environmental factors in the SWAL-QOL, however personal factors are addressed by questions relating to demographic information including ethnicity/race, years of schooling, and marital status.

Advantages – SWAL-QOL

The SWAL-QOL can be self-administered, administered by an interviewer, or can be completed by a proxy, such as a friend or family member (McHorney et al., 2000). Statistically, the SWAL-QOL has adequate content validity, with all items demonstrating acceptable internal consistency (see Table II). Although originally designed for an English-speaking population, the SWAL-QOL has since been validated in Dutch (Bogaardt et al., 2009) and French (Khaldoun, Woisard, & Verin, 2009) populations. The SWAL-QOL provides a holistic approach to dysphagia assessment, as evidenced by the inclusion of items that cover all WHO ICF domains.

Limitations – SWAL-QOL

The SWAL-QOL takes longer to complete compared to other swallowing questionnaires reviewed in this paper. The longer administration time results in increased clinical burden and may limit the widespread use of the SWAL-QOL in clinical practice (Belafsky et al., 2008). The complexity of the wording in the SWAL-QOL also restricts its use in populations with lower literacy levels (Silbergleit et al., 2012). The wording of the SWAL-QOL is argued to be more complex compared to similar assessments (Zraick et al., 2012), and the patient may require increased cueing to complete the tool, further contributing to clinical burden (Silbergleit et al., 2012).

The Deglutition Handicap Index (DegHI) (Woisard, Andrieux & Puech, 2006)

The Deglutition Handicap Index (DegHI) was created by a group based in France following evaluation of existing swallowing questionnaires. The authors found that preexisting questionnaires were designed for a specific etiology or patient group (level of illness severity), and had not been translated into French. Formatted to mirror the ‘Voice Handicap Index’, the DegHI consists of 30 swallowing related aspects in daily life. It is subdivided in three domains of 10 items: physical (symptoms), functional (nutritional and respiratory consequences) and emotional (psychosocial consequences). Each item is answered on a 5 point rating scale (where 0 = never, 1 = almost never, 2 = sometimes, 3 = almost always, 4 = always). The DegHI was validated in a group of 149 individuals, consisting of a 53-strong control group (including SLP students and professors, patients’ family members, and employees of a functional education center), and 96 patients with varying pathologies, of whom 25 had a progressive neurological illness. The authors hypothesized that for the Physical domain, reported symptoms would correlate with radiological examination of swallowing. For the Functional domain, in the absence of a test measuring respiratory impact, the authors correlated the responses with nutritional status using the ‘Nutritional Risk Screening’, Body Mass Index (BMI), and a measurement of meal duration. For the validity of the Emotional domain (psychological impact), scores were correlated with COOP/WONCA charts, which evaluate the QOL of patients with chronic illnesses (Woisard, Andrieux, & Puech 2006).

The DegHi addresses multiple WHO ICF domains (see Table IV), including Body Function and Structure, Activity, and Participation.

Advantages – DegHI

The DegHI is not disease-specific, making it an appropriate tool for use in a variety of dysphagia groups. The probe statements are short in length, making the DegHI appropriate for patients with early cognitive decline.

Limitations - DegHI

The DegHI has not been evaluated in longitudinal studies and therefore its effectiveness in the measurement of dysphagia progression over time is unknown.

The Dysphagia Handicap Index (DHI) (Silbergleit et al., 2012)

The Dysphagia Handicap Index (DHI) was developed to measure the emotional, functional, and physical impact of dysphagia on a person's life. The items in DHI are based on 60 dysphagia–related statements from patients collected by the study authors. These 60 statements were reduced to create a 25-item test consisting of a 9-item physical scale, a 7-item emotional scale, and a 9-item functional scale. Each probe statement is scored by the patient according to personal applicability, including 'never', 'sometimes', and 'always'. All scores are added to provide a total DHI score. Additionally, patients are asked to indicate their overall swallowing severity at the completion of the assessment. This interval scale ranges from 1 to 7, where 1 = ‘normal’, and 7 = ‘severe problem’) (Silbergleit et al., 2012).

The final version of the DHI was validated in a group of 63 individuals with dysphagia (40 females, mean age = 60.3 years, and 23 males, mean age = 65.5 years). The subjects were divided into groups according to their medical diagnosis. Twenty-six (41.3%) presented with neurological impairment (including PD and ALS). The whole sample was compared with 74 healthy controls (40 females, mean age 55.8, 34 males, mean age 53.5) randomly selected from the community. The control group consisted of adults without any known dysphagia, or history of medical conditions associated with dysphagia (Silbergleit et al., 2012).

The three subscales of the DHI are designed to cover multiple domains of the WHO ICF (see Table IV). The physical subscale consists of 10 statements relating to body function and structures. Seven items in the DHI relate to activity related to eating and drinking. Questions relating to participation probed for emotions associated with eating and drinking, including embarrassment, depression, enjoyment, nervousness, anger, feelings of handicap, and fear.

Advantages – DHI

The DHI is not disease-specific, and can therefore be used in dysphagic populations of various etiologies (Silbergleit et al., 2012). The language used in the probe statements is easily understood, making the DHI appropriate for patients with lower literacy levels.

Limitations – DHI

In the original validation study, most of the participants reported mild to moderate dysphagia, with only a few reporting severe symptoms. Therefore, the relationship between the variability of response to dysphagia therapy is unknown. Further comparisons between the results of the DHI and instrumental analysis, such as VFSS, would provide a quantitative analysis. The authors also acknowledge that limiting patient responses to three choices may have also affected DHI sensitivity, due to reduced variability in patient responses (Silbergleit et al., 2012).

<u>Table III</u> – Measurement Properties

Screening Tool	**Reliability**	**Validity**	**Sensitivity/specificity**
Dysphagia in Multiple Sclerosis Questionnaire (DYMUS)	*Internal consistency:* Total Cronbach's alpha coefficient (α). - Total 0.914 - Dysphagia for solids 0.885 - Dysphagia for liquids 0.864 (Bergamaschi et al., 2009).	1734 MS patients across 13 MS centers were assessed. 31% (541) recorded at least one abnormal response on the DYMUS, indicating the presence of dysphagia. The mean score in the validation group was 1.31 (SD 2.49, range 0-10). 527/1734 patients subjectively reported swallowing problems and had significantly higher mean scores than the other 1207 patients (4.19 ± 3.24 vs. 0.30 ± 0.97, Mann-	Not documented.

		Whitney test, p<0.001) (Bergamaschi et al., 2009).	
Dysphapark Questionnaire	*Internal consistency:* Person Separation Index (PSI) • Swallowing efficiency 0.792 • Swallowing safety 0.811	79.45% (n=317) participants reported awareness of swallowing problems. Of these, 56.5% (n=179) had both swallowing efficacy, and swallowing safety problems, 25.6% (n-81) had efficacy only, and 6.3% (n=20) has only safety issues. 11.7% (n=37) had no subjective symptoms of dysphagia. *Dimensionality:* Preliminary Rasch analysis of the 21 items confirmed that the tool was not	Not documented

		unidimensional. The swallowing efficiency subscale demonstrated weakness in the response categories, where no significant difference was seen between the middle two response categories ‘often’ and ‘sometimes’. The swallowing safety subscale was deemed unidimensional with a percentage of 6.59% (CI 95%), determined via *t* test (Bayés-Rusiñol et al., 2011).	
Eating Assessment Tool (EAT-10)	*Internal consistency:* Cronbach’s alpha coefficient (α) 0.96 *Test-retest reliability:* Pearson	Validity was determined by administering the EAT-10 before and after dysphagia treatment, and	Not documented.

	product coefficient ranged from 0.72 to 0.91 (Belafsky et al., 2008).	by evaluating the assessment results of controls versus people with known dysphagia. The mean EAT-10 score of dysphagic patients improved from 19.87 ± 10.5 to 5.2 ± 7.4 after treatment ($p < 0.001$) (Belafsky et al., 2008).	
Radboud Oral Motor Inventory for PD (ROMP)	*Internal consistency:* Cronbach's alpha coefficient (α) - • ROMP total: 0.95 • Speech subscale: 0.92 • Swallowing subscale: 0.87 • Saliva control subscale: 0.94 *Test-retest:* Determined by repeated assessment of 60 patients	*Construct Validity:* Comparison of ROMP with measures of disease severity and oral motor functioning - 0.61 to 0.58 (significant at < 0.05 level) (Kalf et al., 2011).	Not documented.

	within a mean of 24 ± 12 days. Intraclass correlation coefficient (IC) for swallowing subscale = 0.86, with test-retest reliability r > 0.70 (Kalf et al., 2011).		
Swallowing Disturbance Questionnaire (SDQ)	*Internal consistency:* Cronbach's alpha coefficient (α) 0.8 (Cohen & Manor, 2011).	92% of patients with SDQ score of 11 (optimal score) had swallowing disturbances confirmed by physical examination; 38% of patients with total SDQ score 11 had swallowing disturbances on physical examination (Manor et al., 2007).	When SDQ responses regarding the oral phase of swallowing were correlated with findings from an oro-motor examination, sensitivity was 85.7%, and specificity was 87.6%. When responses focusing on the phase of swallow were compared with FEES examination, sensitivity was 67.3% and specificity was 76.7%. When the total SDQ score was correlated with the total

			oral motor and the FEES scores, overall sensitivity was 79.7% and specificity was 73% (Cohen & Manor, 2011)
Swallowing Quality of Life (SWAL-QOL) questionnaire	*Internal consistency:* Measured for each SWAL-QOL domain by calculating Cronbach's alpha coefficient (α). Reliability estimates greater than 0.80 were deemed satisfactory for group-level research, while coefficients of 0.95 or greater are necessary for individual patient decision making. *Test-retest:* Established for each assessment domain using Pearson's correlation coefficient	*Convergent validity:* Results of SWAL-QOL completed by dysphagic and non-dysphagic patients compared with Medical Outcomes Study (Stewart, Hays et al. 1988) - Health perceptions - r=0.11 to 0.50, Social function - r=0.24 to 0.49, Loneliness - r=0.29 to 0.56, Mental health - r=0.20 to 0.52 (McHorney et al., 2002).	Not documented.

	(P) and intraclass correlation (IC). A value greater or equal to than 0.75 is considered excellent. • Food selection - α 0.89, P 0.83, IC 0.83 • Burden - α 0.89, P 0.60, IC 0.59 • Mental health- α 0.94, P 0.80, IC 0.80 • Social functioning- α 0.94, P 0.88, IC 0.89 • Fear - α 0.79, P 0.74, IC 0.74 • Eating duration - α 0.80, P 0.64, IC 0.64 • Eating desire - α 0.86, P 0.91,		

	IC 0.91 - Communication - α 0.91, P 0.76, IC 0.76 - Sleep - α 0.81, P 0.80, IC 0.81 - Fatigue - α 0.90, P 0.85, IC 0.85 (McHorney et al., 2002).		
Sydney Swallow Questionnaire (SSQ)	*Test-re-test:* Delta scores were calculated for each individual item on the SSQ. Delta values for normalized scores ranged from -2% to 17%. The confidence intervals for all delta values neared 0, indicating that no retest score differed significantly from its	*Face Validity:* 25/32 (78%) authorities in the field of dysphagia responded to face-validity survey. 14/ 19 (74%) questions were rated as moderately or highly relevant by more than 80% of respondents. *Construct Validity:* The total	Not documented.

	baseline score (Wallace et al., 2000).	inventory score demonstrated high linear correlation with global assessment score, where $r = 0.69$, $P < 0.0001$) (Wallace et al., 2000).	
The Deglutition Handicap Index (DegHI)	*Internal consistency:* Cronbach's alpha coefficient (α) - • Physical (symptoms) - 0.60 • Functional (nutritional and respiratory consequences) - 0.74 • Emotional (psychological consequences) - 0.88 • Total - 0.90 • Total combined score of a dysphagic group and a group of	*Criterion validity:* • Physical: Correlated with instrumental analysis (VFSS) Total VFSS – r 0.252, Stasis – r 0.295, Choking – r 0.168 (no significant results) • Functional: Correlated with the 'Nutritional Risk Screening', Body Mass Index (BMI), and meal duration. Significant correlation found	Not documented.

	healthy controls – 0.81 (Woisard, Andrieux, & Puech, 2006). *Test-re-test:* Performed at an interval of two weeks and measured with intraclass correlation coefficient (IC) - Physical 0.77 (0.64-0.90) - Functional 0.87 (0.79-0.94) - Emotional 0.90 (0.84-0.96) - Total 0.91 (0.85-0.96) (Woisard & Lepage, 2010)	between the functional domain and meal duration (r = 0.319 where p = 0.035). Emotional (correlated with COOP/WONCA cards): r = 0.040 (not significant) (Woisard, Andrieux, & Puech 2006).	
The Dysphagia Handicap Index (DHI)	*Internal Consistency:* Determined by calculating Cronbach's alpha coefficient (α). All subscales	*Criterion Validity:* Assessed using VFSS. A subgroup of patients (n=60) underwent VFSS and were	Not documented.

	received significant scores. • Total scale - α 0.94. • Physical scale – α 0.78 • Functional scale – α 0.91 • Emotional scale – α 0.86 *Test-retest reliability:* Determined by calculating Pearson's correlation coefficient (PC) between scales, and intraclass correlation coefficient (IC). • Total - P 0.83, IC 0.83 • Physical scale – P 0.77, IC 0.77 • Functional scale – P 0.86, IC 0.86 • Emotional scale – P 0.75, IC	divided into severity groups based on results - normal (n=19), mild (n-29), and moderate/severe (n=12). A significant difference was found between these severity groups (as measured by ANOVA methods): • Total DHI – p = 0.003 • Physical scale – p = 0.049 • Functional scale – p = 0.001 • Emotional Scale – p = 0.009 *Construct Validity:* Pearson correlations were conducted between scales. • Emotional and Functional	

	0.75 (Silbergleit et al., 2012).	Scales – r = 0.77 • Physical and Functional Scales – r = 0.72 • Physical and Emotional Scales – r = 0.66 Wilcoxon two-sample tests were used to compare the dysphagia and control groups in the original validation study. The control group demonstrated lower scores for all scales compared to the dysphagia group (p < 0.001 for the total score, and each individual subscale). Close to all participants in the control group	

		marked zero or ‘never’, indicating perceived normal swallowing. (Silbergleit et al., 2012)	

Table IV - Application of the WHO ICF model to self-reported assessment tools for dysphagia

See Appendix 1 for a detailed outline of each assessment's individual items in relation to the WHO ICF framework.

			WHO ICF Domains		
Screening Tool	**Health Condition**	**Body Functions and Structures**	**Activity – Swallowing (S) and related to Eating and Drinking (ED)**	**Participation**	**Contextual factors – Environmental (E) and Personal (P)**
Dysphagia in Multiple Sclerosis (DYMUS) Questionnaire	X	√	√	X	X
Dysphapark Questionnaire	X	√	X	X	X

Eating Assessment Tool (EAT-10)	X	√	√	√	X
Radboud Oral Motor Inventory for Parkinson's Disease (ROMP) (Swallowing subtest)	X	√	√	√	X
Swallowing Disturbance Questionnaire (SDQ)	X	√	X	X	X
Swallowing Quality of Life (SWAL-QOL) Questionnaire	√	√	√	√	√

Sydney Swallow Questionnaire (SSQ)	√	√	X	√	√
The Deglutition Handicap Index (DegHI)	X	√	√	√	X
The Dysphagia Handicap Index (DHI)	X	√	√	√	X

Discussion

Here we present a review of self-reported swallowing assessments used in progressive neurological disorders. The clinical utility of each tool was determined by comparing the psychometric properties (e.g., reliability, validity) of each tool as well as the degree of coverage of the domains of the WHO ICF framework. Our search identified nine self-report swallowing assessment tools designed for use in our target population (neurodegenerative diseases). Of those nine assessments, the SWAL-QOL yielded the strongest combination of reliability (including internal consistency and test-retest reliability), validity, and clinical application (including adherence to the WHO-ICF framework). A recent review examining the psychometric properties of four QOL questionnaires (including the SWAL-QOL, DegHI, and DHI) relating to dysphagia unspecific to neurodegenerative populations found similar results (Timmerman, Speyer, Heijnen, & Klijn-Zwijnenberg, 2014). Lengthy administration time was identified as a weakness of the SWAL-QOL, as well as published psychometric data on only a relatively small population of people with neurodegenerative disease (n=49, or 12.7% of the participant group of 386).

Psychometric evaluation methodology varied amongst the assessment tools we identified. Reliability was determined using Cronbach's alpha coefficient (α) for all but two assessments: the Dysphapark Questionnaire (where internal consistency was determined using the Person Separation Index – PSI) and the SSQ (where test re-test reliability was determined using Delta scores). Of the tools which used α to determine internal consistency, all but the SWAL-QOL provided a total α value. For the SWAL-QOL, α was determined for each separate assessment domain. Five tools achieved excellent internal consistency (where $\alpha \geq 0.9$). The EAT-10 yielded the highest total internal consistency (α 0.96), followed by the 'Mental Health' and 'Social Functioning' domains of the SWAL-QOL (α 0.94. The remaining subscales ranged from α 0.91 for 'Communication' to 0.79 for 'Fear'), the DHI (α 0.94), the DYMUS (total α 0.914), and the DegHI (α 0.90). Whilst the ROMP scored a total α value of 0.95, the swallow subscale only achieved a 'good' rating of 0.87. Of the 10 SWAL-QOL domains, four achieved α values greater than 0.90 ('Mental Health' – α 0.94, 'Social Functioning' – α 0.94, 'Communication' - α 0.91, and 'Fatigue' – α 0.90). Test-retest reliability was calculated for six of the assessments we evaluated. The Intraclass correlation coefficient (IC) was calculated in four of these tools and ranged from 0.91 (DegHI, and the ‘Eating Desire’ subtest on the SWAL-QOL) to 0.83 (DHI) (ROMP – 0.86). Person’s Correlation was highest in the ‘Communication’ subtest of the SWAL-QOL (0.91) and the EAT-10 (0.91), indicating a high degree of test-retest correlation. Test-retest reliability for the SSQ was determined using Delta values which determines no retest score differed from baseline score in repeated assessments (Wallace et al., 2000).

Like reliability, the methodology for determining validity also varied amongst the tools we identified. Of the tools which achieved excellent internal consistency, the DHI showed the most significant construct validity calculated between the subscales, where r = 0.77 when calculated between the ‘Emotional’ and ‘Functional’ scales. The SWAL-QOL was validated against a separate measure – the Medical Health Outcomes Survey (MOS) (Stewart, Hays et al. 1988). Pearson’s r value was positive across all subscales of the MOS (Health perceptions - r=0.11 to 0.50, Social function - r=0.24 to 0.49, Loneliness - r=0.29 to 0.56, Mental health - r=0.20 to 0.52), indicating strong convergent validity.

Beyond psychometric qualities, assessments were evaluated in relation to clinical burden and application of the WHO-ICF. Only one tool (the SWAL-QOL) addressed all WHO ICF domains, following by the SSQ which covered all domains except ‘Activity’. Although psychometrically strong, the EAT-1O and the DHI only addressed three ICF domains (‘Body Function and Structures’, ‘Activity’, and ‘Participation’) (refer to

Appendix 1). Despite its advantages, the SWAL-QOL remains limited by lengthy administration time (e.g. average 15 minutes). This is particularly pertinent in the neurodegenerative population, where fatigue and cognitive decline may be an issue, impacting on a person's ability to attend to and complete a lengthy assessment. Administration times of the DYMUS, DQ, ROMP, DegHI, and DHI were not discussed in the corresponding literature (refer to Table I). For the remaining four tools, administration times varied from less than two minutes (EAT-10), to 15 minutes (SWAL-QOL).Evaluation of the psychometric properties of any assessment can be influenced by the demographic features of the tested population, such as cognitive function, level of education, ethnicity, gender, and age. Acknowledgement and control for possible cognitive impairment is particularly pertinent to the neurodegenerative population, where cognitive decline is expected in some cases. In its development, the SWAL-QOL was controlled for differences in age, sex, race, and education between the dysphagic and control groups (McHorney et al., 2002). The ROMP appeared to be the only tool that specifically controlled for cognitive impairment, by designing the probe statements so that every item was repeated in the response possibility. The EAT-10 was designed specifically to be easily understood with high 'readability' (Belafsky et al., 2008), arguably controlling for possible cognitive impairment. The length and administration time of the SWAL-QOL could make it difficult for people with cognitive impairment to complete, where attention and comprehension may be an issue. There is an argument that as cognitive function deteriorates the method of dysphagia assessment should alter to accommodate the patient's needs. Therefore reverting to another tool which is shorter with higher readability, such as the EAT-10, could be appropriate as the disease progresses and cognitive function declines. Another option may be relying on proxy or carer reports, as opposed to self-report. However, this may be problematic with some assessments, such as the ROMP which showed low patient-proxy agreement (Kalf et al., 2011).

Subjective reporting of dysphagia is an important but often neglected component of any clinical swallowing assessment. This study identified and reviewed self-reported swallowing assessments suitable for use in neurodegenerative diseases. We evaluated and compared each tool according to its psychometric properties, clinical utility, and application to the WHO ICF. All nine tools reviewed have been used in, or were primarily developed for neurodegenerative populations. All tools have published data on psychometric analysis, however for most tools this information was limited, highlighting the need for further research in this field. Of the nine tools identified, the SWAL-QOL presented with the strongest combination of psychometric properties (including reliability and validity) and adherence to the WHO ICF framework.

Conclusion

Routine screening for dysphagia and assessment of subjective swallowing difficulties in neurodegenerative populations requires the use of a reliable and well-validated assessment tool. Data from our review suggest a preference for the SWAL-QOL over other tools, based on psychometric evaluation and clinical utility, including adherence to the WHO ICF framework. Supporting literature has also identified the SWAL-QOL as an appropriate tool to subjectively assess swallowing function (Timmerman et al., 2014).

Other standout tools identified in this review for potential use in people with neurodegenerative disease include the DHI and the EAT-10. In particular, the EAT-10 demonstrated excellent internal consistency, high readability, and is short in length, making it an appropriate alternative for patients with cognitive impairment. A potential limitation of the EAT-10 was the limited coverage of WHO ICF domains. To promote an informed selection of assessment tools, further validation and evaluation of the availability and properties of the tools currently available is required.

The authors declare that they have no conflict of interest.

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APPENDIX 1 - Application of the WHO ICF to self-rated swallowing assessments.

	WHO ICF Domains				
Assessment	**Health Condition**	**Body Functions (F) (physiological functions of body systems) and Structures (S) (anatomical parts of the body such as organs limbs, and their components).**	**Activity – Swallowing (S) and Related to Eating and Drinking (ED)**	**Participation**	**Contextual factors – Environmental (E) and Personal (P)**
Dysphagia in Multiple Sclerosis Questionnaire (DYMUS)		• Do you have difficulties swallowing solid food (such as meat, bread, and the like)?	• Do you need to cut food in small pieces before swallowing? (ED)		

		(F) • Do you have weight loss? (F) • Do you have difficulties swallowing liquid (such as water, milk, and the like)? (F) • Do you have a globus sensation in your throat during swallowing? (F) • Do you			

		have food sticking in your throat? (F) • Do you cough or do you have a choking sensation after solid ingestion? (F) • Do you cough or do you have a choking sensation after liquid ingestion? (F) • Do you need to swallow			

		more and more times before completely swallowing solid food? (F) - Do you need to take more and more sips before completely swallowing liquid? (F)			
Dysphapark Questionnaire		- Drool at rest (F)? - Drool when speaking (F)? - Does liquid spill from the	-		

		mouth when drinking? (F) • Does food come out of your mouth? (F) • Do you chew solid foods (meat, chicken…)? (F) • Does food stick on the roof of your mouth? (F) • Do you have food remaining in your mouth? (F) • Do you			

		have food remaining in your neck? (F) • Do you need to swallow more than once to clear food from your mouth? (F) • Do you cough when you swallow? (F) • Cough when drinking water? (F) • Hoarse after drinking? (F)			

		- Cough with solids (chicken, meat)? (F) - Cough with semisolids, such as yoghurt or custard? (F) - Cough with mixed food (liquid and solid), such as orange or tomato? (F) - Cough with dry food types (bread,			

		crackers, nuts)? (F) • Is food going into your nose? (F)			
Eating Assessment Tool – 10 (EAT-10)		• I cough when I eat (F) • Swallowing liquids takes extra effort (F) • Swallowing solids takes extra effort (F) • Swallowing pills takes extra effort (F) • Swallowing is painful (F) • When I		• My swallowing problem interferes with my ability to go out for meals • The pleasure of eating is affected by my swallowing • Swallowing is stressful	

		swallow food sticks in my throat (F) - My swallowing problem has caused me to lose weight (ED)			
Radboud Oral Motor Inventory for Parkinson's Disease (ROMP)		- How many times do you choke when eating or drinking? (F) - Are you concerned about your difficulty swallowing? (F) - How		- Does your swallowing difficulty limit your dining with others?	

		bothered are you as a result of your difficulty swallowing? (F) • Are you limited during drinking? (S) • Are you limited during eating? (S) • Do you have difficulty swallowing pills? (S)			
Swallowing Disturbance Questionnaire (SDQ)		• Do you experience difficulty chewing			

		solid food, like an apple, cookie or a cracker? (F) • Are there any food residues in your mouth, cheeks, under your tongue or stuck to your palate after swallowing? (F) • Does food or liquid come out of your nose when you eat or			

		drink? (F) • Does chewed-up food dribble from your mouth? (F) • Do you feel you have too much saliva in your mouth; do you drool or have difficulty swallowing your saliva? (F) • Do you need to swallow chewed-up food			

		several times before it goes down your throat? (F) • Do you experience difficulty in swallowing solid food (i.e., do apples or crackers get stuck in your throat)? (F) • Do you experience difficulty in swallowing pureed			

		food? (F) • While eating, do you feel as if a lump of food is stuck in your throat? (F) • Do you cough while swallowing liquids? (F) • Do you cough while swallowing solid foods? (F) • Do you experience a change in your			

		voice, such as hoarseness or reduced intensity immediately after eating or drinking? (F) • Other than during meals, do you experience coughing or difficulty breathing as a result of saliva entering your windpipe? (F)			

		• Do you experience difficulty in breathing during meals? (F) • Have you suffered from a respiratory infection (pneumonia, bronchitis) during the past year? (F)			
Swallowing Quality of Life Questionnaire (SWAL-QOL)	• Feel weak? • Feel tired? • Feel exhausted?	• Coughing (F) • Choking when you eat food (F) • Choking	• It takes me longer to eat than other people	• Dealing with my swallowing problem is very difficult. • My	No direct questions pertaining to Environmental Factors, however Personal

	• In general, would you say your health is – poor, fair, good, very good, or excellent?	when you take liquids (F) • Having thick saliva or phlegm (F) • Gagging (F) • Drooling (F) • Problems chewing (F) • Having excess saliva or phlegm (F) • Having to clear your throat (F) • Food sticking in your throat (F)	(ED) • It takes me forever to eat a meal (ED) • Figuring out what I can and can’t eat is a problem for me (ED) • It is difficult to find foods that I both like and can eat	swallowing problem is major distraction in my life. • Most days, I don’t care if I eat or not. • I’m rarely hungry anymore. • I don’t enjoy eating anymore • I do not go out because of my swallowing problem • My swallowing problem	Factors are addressed by probing for demographic information, such as ethnicity/race, years of schooling, and marital status.

		• Food sticking in your mouth (F) • Food or liquid dribbling out of your mouth (F) • Food or liquid coming out your nose (F) • Coughing food or liquid out of your mouth when it gets stuck (F) • It's been difficult	(ED) • Do you now take any food or liquid through a feeding tube? (ED) • Please circle the letter of the one description below that best described the consiste	makes it difficult to have a social life • My usual work or leisure activities have changed because of my swallowing problem • My role with family and friends has changed because of my swallowing problem	

		for me to speak clearly (F) • Have trouble falling asleep? • Have trouble staying asleep? (F) • I fear I may start choking when I eat food (F) • I worry about getting pneumonia (F) • I am afraid of choking when I drink	ncy or texture of the food you have been eating most often in the last week? (normal diet, soft foods, blended foods, most nutrition through tube feeding, all		

		liquids (F) • I never know when I am going to choke (F) • My swallowing problem depresses me (F) • Having to be so careful when I eat or drink annoys me (F) • I’ve been discouraged by my swallowing problem (F) • My	nourishment through a tube) (ED) • Please circle the letter of the one description below that best described the consistency of liquids you have been drinking most		

		swallowing problem frustrates me (F) • I get impatient dealing with my swallowing problem (F) • People have a hard time understanding me (F)	often in the last week? (liquids such as water, milk, tea, fruit juice and coffee, thick liquids such as tomato juice or apricot nectar, moderately thick liquids such as a		

			milkshake or smoothie, thick liquids such as pudding, or no liquids via the mouth) (ED)		
Sydney Swallowing Questionnaire (SSQ)	• How do you rate the severity of your swallowing problem today?	• Do you have any difficulty starting a swallow? (F) • When you swallow does food or liquid go up behind		• How much does your swallowing problem interfere with your enjoyment of quality of life?	• How long does it take you to eat an average meal? (E) • How much difficulty do you have swallowing thin liquids?

		your nose of come out of your nose? (F) • How much difficulty do you have swallowing at present? (F) • Do you have any difficulty swallowing your saliva? (F) • Do you ever have a feeling of food getting stuck in your throat			(E) • How much difficulty do you have swallowing thick liquids? (E) • How much difficulty do you have swallowing soft foods? (E) • How much difficulty do you have swallowing hard foods? (E) • How much difficulty

		when you swallow? (F) • Do you ever cough or choke when swallowing solid foods? (F) • Do you ever cough or choke when swallowing liquids? (F) • Do you ever need to swallow more than once for your food to go down? (F)			do you have swallowing dry foods? (E)

		• Do you ever cough up or spit out food or liquids during a meal? (F)			
The Deglutition Handicap Index (DegHI)	•	• I feel discomfort when I swallow (F) • The food sticks or stays blocked in my throat (F) • I have difficulty swallowing liquids (F) • I cough or clear my	• I am unable to eat certain foods because of my swallowing difficulties (S) • I have to modify the consistency of the food	• I avoid eating with other because of my swallowing difficulties • My swallowing problem limits my personal or social life • I am bothered by the way I eat	

		throat during or after a meal (F) • I suffocate when eating or drinking (F) • I feel food or liquid coming up after a meal (F) • I have difficulty chewing (F) • Food comes up to my nose when I drink or eat (F) • I dribble	in order to swallow (S) • It takes longer to eat a meal because of my swallowing difficulties (ED) • I eat less because of my swallowing problems (ED) • I am	during a meal • Eating has become a disagreeable time because of my swallowing problems • I find that others do not understand my swallowing problems • Others seem to be irritated by my swallowing problems • I am tense when I eat	

		when I eat (F) - My throat hurts when I swallow (F) - I have more trouble breathing since my swallowing problems (F)	still hungry or thirsty after a meal (ED) - I am tired because of my swallowing problems (D) - I have lost weight because of my swallowing difficulties (S) - I am	with others because of my swallowing - I am ashamed of my swallowing problem - I feel handicapped because of my swallowing difficulties.	

			afraid of eating (ED) I have had bronchitis or pulmonary infections more often since my swallowing problems (S)		
The Dysphagia Handicap Index (DHI)		• I cough when I drink liquids (F) • I cough when I eat	• I avoid some foods because of my swallo	• I’m embarrassed to eat in public • It takes me longer to	

		solid foods (F) • My mouth is dry (F) • I need to drink fluids to wash food down (F) • I’ve lost weight because of my swallowing problem (S) • I choke when I take my medication (F) • I cough up food after I swallow (F)	wing problem (ED) • I have changed the way I swallow to make it easier to eat (ED) • I avoid eating because of my swallowing problem. (ED) • I eat less because of my	eat a meal than it used to • I eat smaller meals more often due to my swallowing problem • I feel depressed because I can’t eat what I want • I don’t enjoy eating as much as I used to • I don’t socialize as much due to my	

		• I have to swallow again before food will go down (F) • I feel a strangling sensation when I swallow (F) • I'm afraid I'll choke and stop breathing because of my swallowing problem (F)	swallowing problem (ED) • I must eat another way (e.g. feeding tube) because of my swallowing problem (ED) • I've changed my diet due to my swallowing proble	swallowing problem • I am nervous because of my swallowing problem • I feel handicapped because of my swallowing problem • I get angry at myself because of my swallowing problem	

			m (ED)		