

Health Related Quality of Life and Oropharyngeal Dysphagia

Virginie Woisard, Florence Sordes

Virginie Woisard, Voice and Deglutition Unit, Department of Otorhinolaryngology and Head and Neck Surgery, University Hospital of Rangueil-Larrey, Toulouse, France

Virginie Woisard, Florence Sordes, Interdisciplinary Research Unit Octogone, EA4156, Mirail University, Toulouse, France

Correspondence to: Virginie Woisard, MD, PhD, Voice and Deglutition Unit, Department of Otorhinolaryngology and Head and Neck Surgery, TSA30030 University Hospital of Rangueil-Larrey, FR-31059 Toulouse, Cedex 9, France

Email: Woisard.v@chu-toulouse.fr

Telephone: +33567771719

Fax: +33567777314

Received: January 31, 2014

Revised: July 9, 2014

Accepted: July 12, 2014

Published online: October 21, 2014

ABSTRACT

The historical development of the “quality of life (QOL)” construct may explain some differences between several kinds of questionnaires of health Related Quality of life (HRQOL). The aim of this paper is to analyse the HRQOL questionnaires used in the field of oropharyngeal dysphagia from a clinical point of view. A systematic search was performed using the electronic databases Pubmed. Only original research articles describing HRQOL questionnaires in oropharyngeal dysphagia were included. Psychometric properties, correlations with generic QOL questionnaires, Severity scales and objective assessments were analysed. Four questionnaires were included: the SWAL-QOL, the MD Anderson Dysphagia Inventory (MDADI), the Deglutition Handicap Index and the Dysphagia Handicap Index (DyHI). Not all criteria for psychometric properties have been adequately met. However, the fundamental properties were validated, i.e. a complete process broadly used in research or clinical practice by the medical community. These questionnaires, such as generic QOL questionnaires, give independent information in the field of oropharyngeal dysphagia. The connections with the severity of the swallowing disorder are moderate and the connections with objective assessment or aetiologic disease are poor. Notwithstanding the appropriate psychometric properties for research, their indication

is limited because (1) no rules are defined for missing answers; (2) when hitting the highest score, no study about the interaction between domains is available; (3) there is no study about the effects of depression and socio economic data; (4) there is no information about the reliability after a long period of time. However, in practice, they help identifying patients’ concerns and understanding their emotional state.

© 2014 ACT. All rights reserved.

Key words: Dysphagia; Quality of life; psychometric validation

Woisard V, Sordes F. Health Related Quality of Life and Oropharyngeal Dysphagia. *Journal of Gastroenterology and Hepatology Research* 2014; 3(10): 1292-1300 Available from: URL: <http://www.ghrnet.org/index.php/joghr/article/view/>

INTRODUCTION

Swallowing difficulties can be a symptom of many different disease processes and are associated with adverse health outcomes: malnutrition, dehydration, pneumonia, depression and death. Impaired swallowing can cause increased anxiety, fear and isolation but also a reduction in the quality of life^[1]. The value of reporting patient-derived outcomes using disease-specific questionnaires has been appreciated for many years^[2] and Quality of life (QOL) measures have largely been utilized in research settings. Their routine usage in clinical settings has been limited and is controversial^[3]. One of the important questions in the routine usage of QOL tools in the clinical arena is the identification of potential barriers and benefits. The most commonly identified barriers include: feasibility of having patients completing the questionnaires, the ability of clinicians to interpret the results, and the scarcity of data demonstrating that QOL data can affect individual patient outcomes^[4].

The aim of this paper is to analyse the health Related Quality of life (HRQOL) questionnaires used in the field of oropharyngeal dysphagia in a clinical point of view. After a historical reminder on the development of the QOL construct, the description of the several Swallowing related QOL questionnaires will lead to a

reflection about what these questionnaires really measure and how they can be used in clinical practice.

THE CONCEPT OF QUALITY OF LIFE

The term “quality of life (QOL)”, born in the seventies, references the general well-being of individuals and societies. Originally, this term seems to have been a political slogan, expressed by Lyndon B. Johnson in 1964 in a message to the American nation. This Slogan meets the heart of the American constitution of Jefferson, which makes happiness an inalienable right of every American Citizen^[5]. The fact remains that this term will have a heightened success ten years later (1978) by the declaration of Alma-Ata of the World Health Organization (WHO)^[6], where «health, which is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector». After this declaration, the researchers in the field of medicine explored other components that symptomatology, morbidity or mortality.

Thus, a broad reflection is created around the implication of functional disorders and autonomy on health. Several concepts emerged such as the «Health Status»^[7] with two resulting measures: (1) Self-rated health (SRH) and (2) health-related quality of life (HRQoL)^[8,9], and some classifications of health and health-related domains by the WHO^[10,11]. The first one was the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (1980). It has triggered a lot of discussions about its concept, definitions and use of the terms handicap and disability. It is why a new International Classification of Functioning, Disability and Health (ICF) was proposed in 2001, where «handicaps» are defined from a more social point of view, taking into consideration opportunities, people’s environment and life roles, depending on individual identity, impairments, and the social context.

Finally, the term “quality of life (QOL)” is used in a wide range of contexts, including the fields of international development, healthcare and politics. In medicine, QOL is a global construct that has developed in response to the perceived need to assess the patient’s overall sense of well-being and how it relates to disease and disease treatment. This view has been supported by the World Health Organization which defines QOL as “an individual’s perception of their position in life, in the context of the culture and values systems in their life, and in relation to their goals, expectations, standards, and concerns”^[12], QOL measures seek to obtain a comprehensive, multi-dimensional picture of the patient’s “total health related experience.” In order to achieve this goal, QOL measures evaluate broad domains including emotional, physical, functional, social, financial and spiritual well-being.

Therefore HRQOL reflects the effect of disease and disease treatment on general well-being. It is a much broader concept than handicap: circumstances which are not related to illness, are also taken into consideration^[11]. QOL research has, at times, failed to provide health care professionals with clinically relevant and interpretable information that can guide treatment decisions. This has led researchers to attempt to make commonly used research tools more accessible to the practicing clinician^[13]. Thus, in spite of the withdrawal of the ICIDH, the use of handicap questionnaires remains available in practice, and specific related QOL questionnaires were created for numerous chronic diseases with a rise in importance of specific and symptom modules.

METHODS

A systematic literature search was performed using the electronic database Pubmed. All appropriate journal articles up to November 2013 were included. To ensure that a comprehensive approach was adopted in order to retrieve relevant publications, mesh and thesaurus terms were supplemented by the help of the Pubmed advanced search builder leading to deglutition disorders AND Quality of life AND questionnaire corresponding to the following search details: ["deglutition disorders"(MeSH Terms)] OR ["deglutition"(All Fields) AND "disorders"(All Fields)] OR "deglutition disorders"[All Fields] AND ["quality of life"(MeSH Terms)] OR ["quality"(All Fields) AND "life"(All Fields) OR "quality of life"(All Fields)] AND ["questionnaires"(MeSH Terms) OR "questionnaires"(All Fields) OR "questionnaire"(All Fields)]. Only original research articles describing HRQOL questionnaires in oropharyngeal dysphagia were included. Case reports and editorials were excluded, as well as questionnaires focused on esophageal dysphagia or gastroesophageal reflux disease or questionnaires mainly focusing on Functional Health Status or severity or functional outcomes or focusing on a specific disease. Reference lists of all included articles were searched for additional literature. Next, an extended search was conducted for each of the included questionnaires to ensure that all articles on their development and validation were retrieved using the names of each questionnaire in combination with their respective acronyms. The psychometric properties of the included questionnaires and their connections with objective assessments, generic quality of life questionnaires and severity scales were analysed.

RESULTS

Swallowing specific related QOL questionnaire

The findings of the literature search resulted in a total of 609 abstracts. 11 original questionnaires were identified. Of those, two HRQOL questionnaires relative to Head and Neck cancer were excluded: the European Organization for Research into the Treatment of Cancer C30 and HN35 questionnaires (EORTC)^[14-16] and the University of Washington quality of life questionnaire UW-QOL^[17,18]. Five questionnaires were excluded because they focus on Functional Health Status: the Eating Assessment Tool (EAT-10)^[19], the Self-report Symptom Inventory^[20] and The Sydney Swallow Questionnaire (SSQ)^[21], the Dysphagia Short Questionnaire^[22], and the Swallowing Disturbance Questionnaire^[23].

Finally, four self-administered questionnaires were included: the SWAL-QOL^[24-27], the MD Anderson Dysphagia Inventory (MDADI)^[28-31], The Deglutition Handicap Index (DHI)^[32-34] and the Dysphagia Handicap Index (DyHI)^[35].

Therefore, several tools were constructed for use in clinical research for patients with oropharyngeal dysphagia. There remains a paucity of health outcomes tools from the patients' perspective, such as quality of life questionnaires.

The validation process of the Swallowing-specific related QOL questionnaires

The first Swallowing-specific related QOL questionnaire was proposed by McHorney *et al*^[24-26]. These authors proposed a patient-based, dysphagia-specific outcomes tool to enhance information on treatment variations and treatment effectiveness: the SWAL-QOL, a quality of life outcomes tool for dysphagia researchers and clinicians. Some psychometrics characteristics were completed by others authors, particularly for clinically relevant difference scores^[27]. This information is critical for the Interpretation of how patients cope with

swallowing problems.

Swallowing troubles are also addressed in most head and neck cancer-specific quality of life Questionnaires, such as the EORTC QLQ-30 and HN35, the FACT-H and N, and the University of Washington Quality of Life Questionnaire^[14,18]. However, to obtain more insight in swallowing impairment in this disease, a swallowing-specific quality of life Questionnaires has also been developed, in 2001: the MD Anderson Dysphagia Inventory (MDADI)^[28]. The aim of its creators was to provide a validated questionnaire that can be used to assess the outcomes perception of swallowing abilities as a result of treatment and how this swallowing dysfunction affects the QOL in head and neck cancer patients. As with the SWALL-QOL, the validation was completed by other authors^[29], in particular for broader range of aetiologies^[30].

The Deglutition Handicap Index (DHI) was created as a clinical tool for swallowing disorders whatever the aetiology of the disorders in 2006^[32] on the model of the Voice Handicap Index^[36]. The aim was to create a clinical practical tool for assessing the impact of swallowing disorder on the patient : simpler and less comprehensive than the Swall-QOL and not specifically built for head and Neck cancer. This questionnaire was first published in French, translated in English^[33,34] and in several European languages by other authors^[31].

The dysphagia Handicap Index (DyHI) is the latest developed questionnaire . The goal was to obtain a clinically efficient tool, easy for most populations to complete and to measure QOL in individuals with a variety of medical diagnoses^[5].

More details of these self-adminitrated questionnaires are described Table 1.

Table 1 Description of SWALL-QOL, MDADI, DHI and DyHI questionnaires .

Tools	Domains	Number of items and responses format	Target population	Control group and other psychometric data	Limit of agreement & Cut-off score
SWALL-QOL [24-28]	10 quality of life domains and a symptom scale. The domains include: (1) Burden, (2) Food selection, (3) Eating duration, (4) Eating desire, (5) Fear (6)Sleep, (7) Fatigue (8) Communication, (9) Mental health, (10) Social functioning.	44 items Responses: Format varies throughout instrument. Mostly in 5 levels in terms of degree of "true" or frequency. All SWAL-QOL scales range from 0 to 100, a higher score indicating more impairment	Broad range of aetiologies N = 386	Control group N = 40	
SWALL-QOL [27]			Head and Neck Cancer -QOL N =102	Control group N = 111	A difference score of 12 points or more is clinically and statistically relevant in comparing groups of patients after treatment for oral or oropharyngeal cancer A cut-off score of 14 points (or higher) was defined regarding the total SWAL-QOL score to identify patients with swallowing problems with 94% sensitivity and 84% specificity
MDADI[28]	1 global assessment and 3 sub- scales: (1) emotional, (2) functional, (3) physical	20 items Responses: Format in 5 five-point scale scores in terms of degree of agreement The Mean score of each subscale X20 for range from 0 to 100, a higher score higher scores indicated higher functioning	Head and Neck Cancer N=100	Control group = 0 Significant difference between different tumor localisations (p<0,001) and benign or malignant tumor (p<0,001)	
Italian MDADI [29]			Head and Neck Cancer N=50	Control group N=48	
MDADI[30]			Head and Neck Cancer and neurologic diseases N=115	Control group N=115	
DHI[32-34]	3 domains: (1) emotional, (2) functional, (3) physical	30 items Responses: Format in 5 point scale scores in terms of frequency The total minimum scores range from zero (indicating no handicap) to 120 (indicating maximum handicap) 25 items	Broad range of aetiologies N = 96	Control group N= 53 Sensitivity to change p = 0.002.	A difference score of 9 points for the subscales and 20 points for the total score or more is statistically relevant in comparing groups A cut-off score of 11 points
DyHI[35]	3 domains: (1) emotional, (2) functional, (3) physical	Responses: Format in 3-point scale scores in terms of frequency	Broad range of aetiology n = 77	Control group N= 74	

The SWAL-QOL, is considered to be the golden standard for determining quality of life in persons with oropharyngeal dysphagia. It is the only one built on a generic QOL model, widely exploring the several aspects of this construct. This 44-item tool exhibits good internal-consistency reliability and short-term reproducibility^[26]. It consists of 11 subscales: 10 quality of life domains and a symptom scale (Table 2).

Table 2 Reliability and short-term reproducibility of the SWAL-QOL^[26].

	Internal consistency Chronbach's alpha	Test-retest Pearson correlation
Food selection	0.89	0.83
Burden	0.89	0.60
Mental Health	0.94	0.80
Social functioning	0.94	0.88
Fear	0.79	0.74
Eating duration	0.80	0.64
Eating desire	0.86	0.91
Communication	0.91	0.76
Sleep	0.81	0.80
Fatigue	0.90	0.85

It is the most frequently used instrument to determine whether oropharyngeal dysphagia impacted the QOL in research. With this goal, it explored the QOL of various aetiologies, such as thyroid disease^[37], patients with oral and oropharyngeal cancer^[27] amyotrophic lateral sclerosis^[38].

The MDADI, the DHI and the DyHI are similar in their structure. They refer to the International Classification of Impairments, Disabilities, and Handicaps with 3 domains: emotional, functional and physical. But, the distribution of similar items is different between the domains of each questionnaire as described in the [table 3](#). The MDADI consists of 20 items. Besides a global assessment corresponding to a single question, it comprises three sub-scales: the emotional (8 items), the functional (5 items), and the physical subscales (6 items). In the original version of the MDADI, all but two items were scored in such a way that higher scores indicate higher functioning.

The DHI is a 30-item questionnaire on deglutition-related aspects of daily life. The questionnaire is subdivided into three domains of ten items: emotional (psychosocial consequences), functional (nutritional and respiratory consequences), and physical (symptoms related to swallowing). Lower scores indicate higher functioning.

The dysphagia Handicap Index is a 25-item test consisting of a 9-item physical scale, 7-item emotional scale, and a 9-item functional scale.

The details of the psychometrics characteristics of the MDADI, DHI, DyHI are reported in [table 4](#)^[24-27, 28-30, 32-35].

The quality of a measurement instrument is dependent upon its measurement properties (reliability, validity, responsiveness). However, there are no widely accepted criteria for good measurement properties^[39]. Speyer *et al*^[31] in a study on the validity and reliability of the Dutch version of the Deglutition Handicap Index (DHI) and the MD Anderson Dysphagia Inventory (MDADI) for oncological patients with oropharyngeal dysphagia concluded that neither of the MDADI and the DHI generates perfect psychometric data. Not all criteria for psychometric properties have been adequately met. But, a complete the psychometric criteria is a long process including a wide use in research or clinical practice by the medical community.

CORRELATIONS WITH GENERIC QUALITY OF LIFE QUESTIONNAIRES AND SEVERITY SCALES, OBJECTIVE ASSESSMENTS

Correlations with generic QOL questionnaire

Except for the DyHI, these questionnaires analyse the convergent validity, i.e. the extent to which a measure corresponds with others measures that assess similar concepts, analysing the correlation with a generic QOL questionnaire. The correlations are moderate ($r=0.38$ to 0.59) but significant with the MOS SF 36^[40] (with the Swal-Qol and MDADI) or the Wonca Coop Charts^[41] (with the DHI). The correlations are the highest for the MOS social functioning and the social functioning scale of the Swal-QOL or the functioning domain of the MDADI. Similarly, the best correlation is found between the functioning domain and the total score of the DHI, and the Wonca coop charts. We can conclude that QOL in oropharyngeal dysphagia is mainly impacted by the functional consequences of swallowing disorders.

Correlations with severity

Since the clinical validity of these scales leads to verification, they allow distinguishing the severity levels of a given condition. For the SWAL-QOL, the major difference concerning the level of severity is observed for fear, food selection, burden and mental health. For the DHI, the functioning domain is again the highest inverse correlated at $r=0.5$. Therefore, the scores of these questionnaires reflect partially the severity of oropharyngeal dysphagia.

Correlations with objective assessments

Some authors explored the connections between objective assessments of swallowing and dysphagia specific QOL questionnaires.

The correlations between the scores of the several domains, the total score of the DHI, and the results of some objective assessments are reported in [table 5](#). Regarding the nutritional status indicators, there is a poor inverse correlation with the BMI (mostly with the physical domain). The best correlation is between the mealtime and the functioning domain ($r=0.31$). As to the results of the videofluoroscopic study (VFS) or Fiberoptic Endoscopic Evaluation of Swallowing (FEES), it is the functioning subscale again that is best correlated to the stasis into the pyriform sinus ($r=0.38$).

The Correlations between the SWAL-QOL and bolus flow measures for liquid swallows^[43] are reported in [table 6](#). All of the statistically significant correlations are small in magnitude ($r < -0.21$). Ten of the significant correlations involve the oral transit duration measure. Seven of the ten SWAL-QOL scales correlate with the total swallow duration (all but food selection, fear, and sleep).

For a validation study of the University of Washington Quality of Life swallowing domain following oropharyngeal cancer^[18], FEES assessment did not correlate well with the patients' subjective measurements and MDADI.

In conformity with these findings, studies comparing the swallowing problems reported by patient questionnaires showed poor correlation with objective measurements^[44-46]. An explanation may be that swallowing dysfunctions are identified in patients who didn't actually perceive any dysphagia symptoms^[47,48], particularly in case of silent aspirations.

Table 3 Listing of the items inside each questionnaire.

	MDADI	DHI	DyHI	Swal-QoL
P	I cannot maintain my weight because of my swallowing problem	I feel a discomfort when I swallow	I cough when I drink liquids	Dealing with my swallowing problem is very difficult
P	Swallowing is more difficult at the end of the day	The food sticks or stays blocked in my throat	I cough when I eat solid food	My swallowing problem is a major distraction in my life
P	People ask me "why can't you eat that?"	I have difficulty swallowing liquids	My mouth is dry	Most days, I don't care if I eat or not
P	I feel that I am swallowing a huge amount of food	I cough or clear my throat during or after a meal	I need to drink fluids to wash food down	It takes me longer to eat than other people
P	I limit my food intake because of my swallowing difficulty	I suffocate when eating or drinking	I've lost weight because of my swallowing problem.	I'm rarely hungry anymore. It takes me forever to eat a meal.
P	Swallowing takes great effort	I feel food or liquid coming up after a meal	I have to swallow again before food will go down	I don't enjoy eating anymore.
P	It takes me longer to eat because of my swallowing problem	I have difficulty chewing	I choke when I take my medication	Coughing Choking when you eat food
P	I cough when I try to drink liquids	Food comes up to my nose when I drink or eat	I feel a strangling sensation when I swallow	Choking when you take liquids
P		I dribble when I eat	I cough up food after I swallow	Having thick saliva or phlegm
P		My throat hurts when I swallow		Gagging Drooling
F	People have difficulty cooking for me	I am unable to eat certain foods because of my swallowing difficulties	I avoid some foods because of my swallowing problem	Problems chewing Having excess saliva or phlegm
F	I feel free to go out to eat with my friends, neighbors and relatives	I have to modify the consistency of the food in order to swallow	I have changed the way I swallow to make it easier to eat	Having to clear your throat Food sticking in your throat
F	My swallowing problems limit my social and personal life	It takes longer to eat a meal because of my swallowing difficulties	It takes me longer to eat a meal than it used to	Food or liquid dribbling out of your mouth
F	I feel exclude because of my eating habits	I eat less because of my swallowing problems	I eat smaller meals more often due to my swallowing problem	Food sticking in your mouth Food or liquid coming out your nose
F	My swallowing difficulty has cause me to loose income	I am still hungry or thirsty after a meal	I don't socialize as much due to my swallowing problem	Coughing food or liquid out of your mouth when it gets stuck
F		I am tired because of my swallowing problems	I avoid eating because of my swallowing problem	Figuring out what I can and can't eat is a problem for me
F		I have lost weight because of my swallowing difficulties	I eat less because of my swallowing problem	It is difficult to find foods that I both like and can eat
F		I am afraid of eating	I must eat another way (e.g., feeding tube) because of my swallowing problem	People have a hard time understanding me
F		I have had bronchitis or pulmonary infections more often since my swallowing problems	I've changed my diet due to my swallowing problem	It's been difficult for me to speak clearly
F		I have more trouble breathing since my swallowing problems		I fear I may start choking when I eat food
E		I avoid eating with others because of my swallowing difficulties	I'm embarrassed to eat in public	I worry about getting pneumonia I am afraid of choking when I drink liquids
E	I'm embarrassed by my eating habits	My swallowing problem limits my personal or social life	I feel depressed because I can't eat what I want	I never know when I am going to choke
E	Other people are irritated by my eating problem	I am bothered by the way I eat during meal	I don't enjoy eating as much as I used to	My swallowing problem depresses me
E	I am upset by my swallowing problem	Eating has become a disagreeable time because of my swallowing problems	I am nervous because of my swallowing problem	Having to be so careful when I eat or drink annoys me
E	I do not go out because of my swallowing problem	My swallowing difficulty constrains me	I feel handicapped because of my swallowing problem	I've been discouraged by my swallowing problem
E	I have low self-esteem because swallowing problem	I find that others do not understand my swallowing problems	I get angry at myself because of my swallowing problem	My swallowing problem frustrates me
E	I do not feel self-conscious when I eat	Others seems to be irritated by my swallowing problems	I'm afraid that I'll choke and stop breathing because of my swallowing problem	I get impatient dealing with my swallowing problem
E		I am tense when I eat with others because of my swallowing		I do not go out to eat because of my swallowing problem
E		I am ashamed of my swallowing problem		My swallowing problem makes it hard to have a social life
E		I feel handicapped because of my swallowing difficulties		My usual work or leisure activities have changed because of my swallowing problem
G	My swallowing ability limits my day-to-day activities		Feel weak? Have trouble falling asleep? Feel tired?	Social gatherings (like holidays or get-togethers) are not enjoyable because of my swallowing problem
			Have trouble staying asleep? Feel exhausted?	My role with family and friends has changed because of my swallowing problem

Table 4 Details of the psychometrics characteristics of the MDADI, DHI, DyHI[28-35].

	Items number	Range	Total Reliability Cronbach's alpha	Test-retest	Median	Observed range	Max control	Control mean	Control SD
DyHI	25	0-100	0.94	0.83	22	0-96	?	2.32	2.71
P	9	0-36	0.78	0.77	11	0-34	?	2.11	2.45
F	9	0-36	0.91	0.86	8	0-34	?	0.14	0.51
E	7	0-28	0.86	0.75	4	0-28	?	0.08	0.40
MDADI	20						81	92.9	7.2
P	8	0-100	0.85	0.86	77	20-100	75	93.8	9.2
F	5	0-100	0.89	0.88	80	10-100	72	92.6	9.2
E	7	0-100	0.85	0.88	68	20-100	67	90.9	9.3
G	1	0-100	0.93	0.69	80	20-100	80	95.5	8.3
DHI	30	0-120	0.9	0.91	33	3-92	11	1.94	6.34
P	10	0-40	0.8	0.77	13	2-33			
F	10	0-40	0.74	0.87	12	0-33			
E	10	0-40	0.88	0.9	7	0-38			

Table 5 Correlations between the scores of the DHI and objective assessment: nutritional data (BMI and Meal time measured in minutes) and Videofluoroscopic assessment data [stasis in mm and penetration aspiration scale (PAS)][42].

	Total P	Total F	Total E	Total DHI
BMI	-0.254*	-0.220	-0.018	-0.163
Meal time (mn)	0.081	0.319*	0.292*	0.3*
Stasis (mm)	0.295*	0.381*	0.154	0.289*
PAS	0.168	0.204	0.09	0.162

Table 6 Correlations between SWAL-QOL and bolus flow measures for liquid swallows (* $p < 0.05$)[43].

	Oral transit duration (s)	Pharyngeal transit duration (s)	Total swallow duration (s)	PAS score
Food selection	-0.08	+0.00	-0.05	-0.13*
Burden	-0.16*	-0.04	-0.09	-0.07
Mental health	-0.21*	+0.02	-0.06	-0.11*
Social functioning	-0.14*	-0.10	-0.10	-0.14
Fear	-0.10	+0.01	+0.00	-0.04
Eating duration	-0.16*	-0.04	-0.09	-0.13*
Eating desire	-0.15*	+0.01	-0.04	-0.10
Communication	-0.16*	-0.13	-0.16*	-0.04
Sleep	-0.09	+0.10	-0.01	-0.00
Fatigue	-0.13*	+0.02	-0.04	+0.00

DISCUSSION

We have four validated questionnaires dedicated to oropharyngeal dysphagia

Each questionnaire was built with several questions exploring dimensions. But the statistical methods looking for the several factors failed to find the different scales underlying the construct^[13,26,30]. For example, in the SWAL-QOL food selection, burden, mental health, social functioning, fear, eating duration, eating desire and communication are the first dimension and are the major contributors to dysphagic-specific QOL. Sleep and fatigue contribute equally to generic quality of life and compose a second dimension of the questionnaire. These results confirm that items specific to the disorder in the field of HRQOL create a homogeneous entity. But, what do they convey?

However, as generic QOL questionnaires, they give independent information. The connections with the severity of the swallowing disorder are moderate and the connections with objective assessment or aetiologic disease are poor. As to an illustration of these observations, e.g. in a study on idiopathic Parkinson disease^[49], no relationships existed between swallow-specific QOL and disease duration or severity. Significant relationships existed between swallow-specific QOL and general health-related QOL ($r(s) = -0.56$,

$p=0.000$) and depression ($r(s) = -0.48$, $p=0.003$).

Swallow-specific quality of life questionnaires have the generic aim to describe how swallowing disorders modify the daily life of people. This kind of questionnaires being measurement instruments, they must have high psychometric properties for comparing the impacts between different groups of patients, as well as patients with different diseases or subgroups of diseases. They are also used to determine the outcomes of several treatments^[50-53].

Used with this aim, it would be important to explore the impact of socioeconomic position and the effect of time on the evolution of the scores^[54]. These data are lacking for the four questionnaires.

These questionnaires are also used in others goals.

Another application in clinical practice is to use it as a screening tool. Thomas L *et al*^[18] have studied whether the SWAL-QOL could be used in future comparative studies for oral and oropharyngeal cancer and in clinical practice to identify patients in need of further diagnostics and/or swallowing rehabilitation services. With this aim, they assess swallowing dysfunction in patients treated for oropharyngeal cancer. The evaluation included three questionnaires: the MDADI, the SWALQOL, the University of Washington Quality of Life (UWQOL) and FEES. They found a clear demarcation between UW-QOL levels and food consistency and texture as measured by the SWALQOL ($r=-0.86$, $P<0.001$). Patients scoring 70 or better in the UW-QOL were notably better in MDADI and the SWALQOL. Hence, a cut-off of below 70 could be regarded as a quick screening tool for swallowing dysfunction.

Zuydam AC *et al*^[55] compared the University of Washington Quality of Life (UWQOL) swallowing domain with the MD Anderson Dysphagia Inventory (MDADI) in relation to the need for interventions for swallowing after about one year of treatment. They concluded that patients who score 100 on the UWQOL do not require swallowing to be further evaluated. Those who score 70 could benefit from the detailed MDADI to help clarifying the specific problem and its impact before being referred to speech and language therapy. Those who score less than 70 should be brought to the attention of speech and language therapists to confirm that appropriate support and intervention are in place.

There are few data about the value of these questionnaires in routine at an individual level for following patients and management decision. Only 2 of them^[27,33] have precised the limit of agreement determining the difference score clinically relevant. Without (1) any rules for missing answers, (2) any study about the interaction between domains when one has a highest score, (3) any information about the effects of depression and socio economic, (4) and any information the reliability after a long period of time, their indication in routine is limited.

Place of these HR-QOL questionnaires in the assessment strategies or questionnaires for oropharyngeal dysphagia

QOL measures seek to obtain a comprehensive, multi-dimensional picture of the patient's "total health related experience". The development of tools to measure this concept led to create HR QOL questionnaires. Their structure is selective and not amenable to change because of the careful psychometric development required to establish a validated questionnaire for multi-centre longitudinal study. This explains probably why the Swall QOL is the less used one in clinical routine.

The three others questionnaires included a symptom inventory in their concept and are a mix between the Functional Health Status and the QOL questionnaire. Giving information on functional and psychosocial consequences, they allow to identify patient concerns and to understand their emotional state. They may avoid mismatch between the patient's priorities and that of health care providers.

Used as such, these questionnaires may have a goal similar to the patients' concern inventory (PCI). The concept of a patients concern inventory (PCI) is wider than that of HR-QOL as it allows patients to formulate an individualized record of their concerns, needs and priorities that can be used as a structure to guide out-patient consultations and promote multidisciplinary care^[56].

This is particularly true in oncology, where the complex needs of cancer patients are recognized as a real challenge leading to the concept of holistic needs assessment (HNA). HNA tools are practical clinical documents and are distinct from psychometrically validated quality of life (QOL) instruments^[57].

The HR QOL questionnaires for oropharyngeal dysphagia are psychometrically validated. They are usually longer than FHS but give information about patients' perception of their trouble. This information is nevertheless insufficient to guide out-patient consultations

Therefore, these questionnaires complete the panel of Tools helping health care professionals to identify, understand and resolve patients' priorities and concerns^[58].

CONCLUSION

In practice, HR-QOL in oropharyngeal dysphagia is very important for knowing and measuring the perception by the patients themselves and the impact on their daily life. Four questionnaires are validated. Only one broadly explores the several domains of the QOL (the SWAL-QOL), the 3 others resemble handicap questionnaires. None of them is validated for being used in routine at an individual level for the follow-up of the patients. Despite their good psychometric properties for research, the lack of correlations with other clinical data and the fact that severe swallowing disorders may be associated to any dysphagia symptoms contribute to this restriction.

REFERENCES

- 1 Vesey S. Dysphagia and quality of life. *Br J Community Nurs* 2013; **S14, S16, S18-9**.
- 2 Rothman ML, Beltran P, Cappelleri JC, Lipscomb J, Teschendorf B. Mayo/FDA Patient-Reported Outcomes Consensus Meeting Group. Patient-reported outcomes: conceptual issues. *Value Health* 2007; **10** S2:S66-S75
- 3 Murphy BA, Ridner S, Wells N, Dietrich M. Quality of life research in head and neck cancer :A review of the current state of the science. *Critical Reviews in Oncology/Hematology* 2007; **62**: 251–267
- 4 Higginson I. Using quality of life measures in the clinical setting. *BJM* 2001; **322**:1297–1300

- 5 Corten Ph. La Qualité de Vie est-elle un concept? Essai de revue critique de la littérature anglo-saxonne. *L'Information Psychiatrique* 1998; **9**: 922-932
- 6 Declaration of Alma-Ata: international conference on primary health care, Alma-Ata, USSR, September 6–12, 1978. http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf.
- 7 Torrance GW. "Toward a Utility Theory Foundation for Health Status Index Model." *Health Services Research* 1976; **11**: 439-469
- 8 Testa MA, Drescher S. Assessment of quality-of-life outcomes. *N Engl J Med* 1996; **343**: 835–40
- 9 Delpierre C, Kelly-Irving M, Munch-Petersen M, Lauwers-Cances V, Datta GD, Lepage B, Lang T. SRH and HrQOL: does social position impact differently on their link with health status? *BMC Public Health* 2012; **10**: 12:19
- 10 Fougeyrollas P. L'évolution conceptuelle internationale dans le champ du handicap : enjeux socio-politiques et contributions québécoises. *Pistes*, 2002 4, 26 p <http://www.bdsp.eshp.fr/Full-text/309256/>
- 11 Cardol M, Brandsma JW, de Groot IJ, van den Bos GA, de Haan RJ, de Jong BA. Handicap questionnaires: what do they assess? *Disabil Rehabil* 1999; **21**: 97-105
- 12 World Health Organization. WHO Health Promotion Glossary 1998. WHO/HPR/HEP/98.1, World Health Organization, Geneva, 1994. Retrieved 6-23-2005 from: [http://208.164.121.55/reference/SOME/Outlines/world health organization.htm](http://208.164.121.55/reference/SOME/Outlines/world%20health%20organization.htm)
- 13 Cella D, Bullinger M, Scott C, Barofsky I. Group vs individual approaches to understanding the clinical significance of differences or changes in quality of life. *Mayo Clinic Proc* 2002; **77**: 384-92
- 14 Hassan SJ, Weymuller EA. Assessment of quality of life in head and neck cancer patients. *Head Neck* 1993; **15**: 485-96
- 15 Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JC. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use international clinical trials in oncology. *J Natl Cancer Inst* 1993; **85**: 365-76
- 16 Bjordal K, Hammerlid E, Ahlner-Elmqvist M, de Graeff A, Boysen M, Evensen JF, Biörklund A, de Leeuw JR, Fayers PM, Janert M, Westin T, Kaasa S. Quality of life in head and neck cancer patients: validation of the European Organization for research and treatment of cancer quality of life questionnaire-H&N35. *J Clin Oncol* 1999; **17**: 1008-19
- 17 Millsopp L, Humphris G, Lowe D, Rogers SN. Patient's response using free text in the University of Washington Quality of Life Scale. *Head Neck* 2003; **25**: 1042-50
- 18 Thomas L, Jones TM, Tandon S, Katre C, Lowe D, Rogers SN. An evaluation of the University of Washington quality of life swallowing domain following oropharyngeal cancer. *Eur Arch Otorhinolaryngol* 2008; **265**(S1): S29-37
- 19 Belafsky PC, Mouadeb DA, Rees CJ, et al. Validity and reliability of the eating assessment tool (EAT-10). *Annals of Otolaryngology, Rhinology and Laryngology*. 2008; **117**: 919-924
- 20 Wallace KL, Middleton S, Cook IJ. Development and validation of a self-report symptom inventory to assess the severity of oropharyngeal dysphagia. *Gastroenterology* 2000; **118**: 678-687
- 21 Dwivedi RC, St Rose S, Chisholm EJ, Bisase B, Amen F, Nutting CM, Clarke PM, Kerawala CJ, Rhys-Evans PH, Harrington KJ, Kazi R. Evaluation of swallowing by Sydney Swallow Questionnaire (SSQ) in oral and oropharyngeal cancer patients treated with primary surgery. *Dysphagia* 2012; **27**: 491-497
- 22 Martin S, Catarina I, Therese E, Claes O. The dysphagia short questionnaire: an instrument for evaluation of dysphagia—a validation study with 12 months follow-up after anterior cervical spine surgery. *Spine* 2012; **37**: 996-1002
- 23 Cohen JT, Manor Y. Swallowing disturbance questionnaire for detecting dysphagia. *Laryngoscope*. 2011; **121**: 1383-1387
- 24 McHorney CA, Bricker DE, Kramer AE, Rosenbek JC, Robbins

- J, Chignell KA, Logemann JA, Clarke C. The SWAL-QOL outcomes tool for oropharyngeal dysphagia in adults: I. Conceptual foundation and item development. *Dysphagia* 2000; **15**: 115-21
- 25 McHorney CA, Robbins J, Lomax K, Rosenbek JC, Chignell K, Kramer AE, Bricker DE. The SWAL-QOL and SWAL-CARE outcomes tool for oropharyngeal dysphagia in adults: II. Item reduction and preliminary scaling. *Dysphagia* 2000; **15**: 122-133
- 26 McHorney CA, Robbins J, Lomax K, Rosenbek JC, Chignell K, Kramer AE, Bricker DE. The SWAL-QOL and SWAL-CARE outcomes tool for oropharyngeal dysphagia in adults: III. Documentation of reliability and validity. *Dysphagia* 2002; **17**(2): 97-114
- 27 Rinkel RN, Verdonck-de Leeuw IM, Langendijk Jan, an Reij EJ, Aaronson NK, Leemans CR. The psychometric and clinical validity of the SWAL-QOL questionnaire in evaluating swallowing problems experienced by patients with oral and oropharyngeal cancer. *Oral Oncology* 2009; **45**: e67-e71
- 28 Chen AY, Frankowski R, Bishop-Leone J, Hebert T, Leyk S, Lewin J, Goepfert H. The development and validation of a dysphagia-specific quality-of-life questionnaire for patients with head and neck cancer: the MD Anderson dysphagia inventory. *Arch Otolaryngol Head Neck Surg* 2001; **127**: 870-6
- 29 Schindler A, Borghi E, Tiddia C, Ginocchio D, Felisati G, Ottaviani F. Adaptation and validation of the Italian MD Anderson dysphagia inventory (MDADI). *Rev Laryngol Otol Rhinol*. 2008; **129**,2: 97-100
- 30 Carlsson S, Rydén A, Rudberg I, Bove M, Bergquist H, Finizia C. Validation of the Swedish M. D. Anderson Dysphagia Inventory (MDADI) in patients with head and neck cancer and neurologic swallowing disturbances. *Dysphagia* 2012; **27**: 361-9
- 31 Speyer RS, Heijnen BJ, Baijens LW, Vrijenhoef FH, Otters EF, Roodenburg N, Bogaardt HC. Quality of Life in Oncological Patients with Oropharyngeal Dysphagia: Validity and Reliability of the Dutch Version of the MD Anderson Dysphagia Inventory and the Deglutition Handicap Index. *Dysphagia* 2011; **26**: 407-414
- 32 Woisard V, Andrieux MP, Puech M. Validation of a self-assessment questionnaire for swallowing disorders (Deglutition Handicap Index). *Rev Laryngol Otol Rhinol (Bord)* 2006; **127**: 315-25
- 33 Woisard V, Lepage B. The "Deglutition Handicap Index" a self-administrated dysphagia-specific quality of life questionnaire: temporal reliability. *Rev Laryngol Otol Rhinol (Bord)* 2010; **131**(1): 19-22
- 34 Crestani S, Moerman M, Woisard V. The "deglutition Handicap Index" a self administrated dysphagia-specific quality of life questionnaire: sensibility to change. *Rev Laryngol Otol Rhinol* 2011; **132**,1: 3-7
- 35 Silbergleit AK, Schultz L, Jacobson BH, Beardsley T, Johnson AF. The Dysphagia handicap index: development and validation. *Dysphagia* 2012; **27**: 46-52
- 36 Jacobson BH, Johnson A, Grywalski C, Silbergleit A, Jacobson G, Benninger MS, Newman CW. The voice handicap index (VHI): development and validation. *Am J Speech lang Pathol* 1997; **6** : 66-70
- 37 Greenblatt DY, Sippel R, Levenson G, Frydman J, Schaefer S, Chen H. Thyroid resection improves perception of swallowing function in patients with thyroid disease. *World J Surg* 2009 Feb; **33**: 255-60
- 38 Paris G, Martinaud O, Petit A, Cuvelier A, Hannequin D, Roppe-neck P, Verin E. Oropharyngeal dysphagia in amyotrophic lateral sclerosis alters quality of life. *J Oral Rehabil* 2013 Mar; **40**: 199-204
- 39 Terwee CB, Bot SDM, de Boer MR, van der Windt DAWM, Knol DL, Dekker J, Bouter LM, de Vet HCW. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol* 2007; **60**: 34-42
- 40 Stewart AL, Hays RD, Ware JE Jr. The MOS short-form general health survey. Reliability and validity in a patient population. *Med Care* 1988; **26**(7): 724-35
- 41 Jamouille M. et coll. Mesure de l'état fonctionnel en médecine générale: les cartes COOP/WONCA. *Rev Méd Brux* 1994; **15**: 329-332
- 42 Rosenbek JC, Robbins JA, Roecker EB, Coyle JL, Wood JL. A Penetration-Aspiration Scale. *Dysphagia* 1996; **11**: 93-98
- 43 McHorney CA, Martin-Harris B, Robbins J, Rosenbek J. Clinical validity of the SWAL-QOL and SWAL-CARE outcome tools with respect to bolus flow measures. *Dysphagia* 2006; **21**: 141-8
- 44 Gillespie MB, Brodsky MB, Day TA, Sharma AK, Lee FS, Martin-Harris B. Laryngeal penetration and aspiration during swallowing after the treatment of advanced oropharyngeal cancer. *Arch Otolaryngol Head Neck Surg* 2005; **131**: 615-619
- 45 Pauloski BR, Rademaker AW, Logemann JA, Lazarus CL, Newman L, Hamner A, MacCracken E, Gaziano J, Stachowiak L. Swallow function and perception of dysphagia in patients with head and neck cancer. *Head Neck* 2002; **24**: 555-565
- 46 Kendall KA, Kosek SR, Tanner K. Quality-of-life scores compared to objective measures of swallowing after oropharyngeal chemoradiation. *Laryngoscope* 2013 Aug 8. doi: 10.1002/lary.24344. [epub]
- 47 Abbes S, Woisard V, Didier A. A clinical respiratory evaluation of dysphagic patients with chronic aspirations. *Rev Laryngol Otol Rhinol (Bord)* 2008; **129**: 79-83
- 48 Nguyen NP, Frank C, Moltz CC, Vos P, Smith HJ, Karlsson U, Dutta S, Midyett A, Barloon J, Sallah S. Impact of dysphagia on quality of life after treatment of head-and-neck cancer. *Int J Radiat Oncol Biol Phys* 2005; **61**:772-778
- 49 Plowman-Prine EK, Sapienza CM, Okun MS, Pollock SL, Jacobson C, Wu SS, Rosenbek JC. The relationship between quality of life and swallowing in Parkinson's disease. *Disord* 2009 Jul 15; **24**(9): 1352-8
- 50 Teguh DN, Levendag PC, Sewnaik A, Hakkesteegt MM, Noever I, Voet P, van der Est H, Sipkema D, van Rooij P, Baatenburg de Jong RJ, Schmitz PI. Results of fiberoptic endoscopic evaluation of swallowing vs. radiation dose in the swallowing muscles after radiotherapy of cancer in the oropharynx. *Radiother Oncol* 2008 Oct; **89**(1): 57-63
- 51 Woisard-Bassols V, Alshehri S, Simonetta-Moreau M. The effects of botulinum toxin injections into the cricopharyngeus muscle of patients with cricopharyngeus dysfunction associated with pharyngo-laryngeal weakness. *Eur Arch Otorhinolaryngol*. 2013 Mar; **270**: 805-15
- 52 Bachy V, Matar N, Remacle M, Jamart J, Lawson G. Long-term functional results after endoscopic cricopharyngeal myotomy with CO2 laser: a retrospective study of 32 cases. *Eur Arch Otorhinolaryngol* 2013; **270**: 965-8
- 53 Argolo N, Sampaio M, Pinho P, Melo A, Nóbrega Do swallowing exercises improve swallowing dynamic and quality of life in Parkinson's disease? *ACNeuroRehabilitation* 2013; **32**: 949-55
- 54 Kelly-Irving M, Delpierre C, Schieber AC, Lepage B, Rolland C, Afrité A, Pascal J, Cases C, Lombrail P, Lang T. Do general practitioners overestimate the health of their patients with lower education? *Soc Sci Med* 2011; **73**: 1416-21
- 55 Zuydam AC, Ghazali N, Lowe D, Skelly R, Rogers SN. Evaluation of the limitations of using the University of Washington Quality of Life swallowing domain alone to screen patients in the routine clinical setting. *Br J Oral Maxillofac Surg*. 2013; **51**: e148-54
- 56 Rogers SN, El-Sheikha J, Lowe D The development of a Patients Concerns Inventory (PCI) to help reveal patients concerns in the head and neck clinic. *Oral Oncol* 2009 Jul; **45**(7): 555-61
- 57 National Cancer Action Team. Holistic Needs Assessment for people with cancer—a practical guide for healthcare clinicians. National Cancer Action Team, 2012, London
- 58 Kanastas, A., Ghazali, N., Lowe, D., & Rogers, S. N. The identification of mood and anxiety concerns using the Patient Concerns Inventory following head and neck cancer. *International Journal*

of Oral and Maxillofacial Surgery 2012; **41**: 429-436

Peer reviewer: M. W. M. van den Brekel, Department of Head and Neck Oncology and Surgery, The Netherlands Cancer Institute, Antoni van Leeuwenhoek Hospital, Amsterdam, The Netherlands; Suely Mayumi Motonaga Onofri, Department of Speech and Language Therapy, São Paulo State University - UNESP, Av. Hygino Muzzi Filho, 737, Campus Universitário, Marília, São Paulo, 17525-900, Brazil.