

# USE OF PROTOCOLS FOR QUALITY OF LIFE IN DYSPHAGIA: LITERATURE REVIEW

## *Utilização de protocolos de qualidade de vida em disfagia: revisão de literatura*

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### ABSTRACT

The purpose of this study was to identify use of life protocols in dysphagia and verify their use in reahbilitation. Was performed a theoretical and exploratory research with the review of the literature technical, on the basis of SCOPUS data, Trip Database, LILACS, PubMed, SciELO, Google Scholar, Capes journals and MedLine. The search time comprised the years between 2004 and 2014 and the following keywords were used: swallowing; swallowing disorders; quality of life; questionnaires and their respective terms in English: deglutition; deglutition disorders; quality of Life; Questionnaires. The protocols found in the literature was the Quality of life in Swallowing Disorders-SWAL-QOL, which establishes the impairment of swallowing independent of the etiology; the MD Anderson Dysphagia Inventory, which is specific for subjects submitted treatment for head and neck cancer and the Dysphagia Handicap Index, which evaluates the effects of dysphagia on quality of life (QOL) in subjects with different pathologies and can be used at lower levels of education. The literature proposes different protocols that assess QoL in dysphagia, the most used to assess QOL in general, related to head and neck cancer and subjects with different medical diagnoses. The use of these protocols can support and complement the clinical and objective evaluation of swallowing once, that portray the self-assessment by the subject, and this view is extremely important for speech therapy.

**KEYWORDS:** Deglutition; Deglutition Disorders; Quality of Life; Questionnaires

### ■ INTRODUCTION

The World Health Organization (1995)<sup>1</sup> after consensus among experts, set Quality of Life (QoL) as an individual's perception about their living conditions in the cultural context and value systems and of the relationship with expectations, goals and concerns of standart. Thus, it is considered QoL as the integrity of multidimensional factors based on physical, mental and social parameters, which may be affected in the presence of dysphagia, and cause social deprivation, isolation and remoteness of the professional ambient <sup>2</sup>.

Dysphagia is related to the change in the form of swallowing, a fact that prevents efficient conduction of the bolus from the digestive tract by affecting different stages of swallowing<sup>3</sup>. This change may cause restrictions on feeding, whether the consistencies or volumes and use of exclusive alternative path or associated with oral<sup>2</sup>.

It is considered a symptom of various diseases base and according to etiology it can be classified mainly mechanical and neurogenic. Among the diseases that result in neurogenic dysphagia stand out from the Cerebral Vascular Accident (CVA), Traumatic Brain Injury (TBI), Parkinson's Disease (PD), Cerebral Palsy (CP) and Neurodegenerative Diseases (ND). In mechanical causes are cancer in the head and neck associated with different types of treatments, traumas, infections, oral prostheses badly adapted, among other functional changes<sup>2,4,5</sup>.

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Among the clinical manifestations can be evidenced difficulties related to chewing, the beginning of the pharyngeal phase of swallowing, the nasal reflux, the cough, the choking during meals, and can result in the intake of food or secretions in the lower airway, implying in penetration, aspiration and aspirative pneumonia, and can also lead to malnutrition and dehydration<sup>3,6,7</sup>.

The change of QoL in dysphagia respect to several adaptations that dysphagic individuals need to perform to have a safe and effective feeding. The new way of eating can bring embarrassment, frustration, depression and social isolation, since the subjects tend to make their meals alone, avoiding eating in the presence of relatives or in public places<sup>2</sup> and for this reason, it emphasizes the need to assess the impact that changes in swallowing and changes in the form of feeding produce in QoL. So, one should take into account the individual's perception regarding his QoL for the adoption of effective measures in speech and language therapy<sup>8</sup>.

Several questionnaires are available in the literature assessing QoL in general, used as indicators of the effectiveness, efficiency and impact of treatments on different diseases, but they do not stress the change of swallowing, or are superficial or they do not deepen this issue<sup>5,9</sup>. Thus, due to sensitivity, specificity and the need to differentiate subjects with normal swallowing of dysphagia affected by various underlying diseases, they were prepared for the detection of dysphagia impact on QoL MD Anderson Dysphagia Inventory questionnaire (MDADI)<sup>10</sup>, Quality of life in Swallowing Disorders – SWAL-QOL<sup>11</sup> and Dysphagia Handicap Index<sup>12</sup>, all translated and adapted to Brazilian Portuguese<sup>5,9,13</sup>.

Given the above, the objective of this study was to review the literature to identify the QoL protocols and verify their use in dysphagia.

## ■ METHODS

Theoretical and exploratory research were effected with the literature review technique. In order to achieve the objective proposed by this work, searches were conducted in SCOPUS databases, Trip Database, LILACS, PubMed, SciELO, Google Scholar, periodicals Capes and MedLine. The search period was the years between 2001 and 2014.

Descriptors in Health Sciences (DeCS, 2014) used for locating the articles were swallowing; swallowing disorders; quality of Life; questionnaires. The search was carried out by individual descriptors and later the association between them.

In this review, 29 references were listed, such as: seven book chapters; three monographs, dissertations and theses; four national papers and fifteen international papers, and excluded studies that affected the theme were listed.

The references were grouped according to the themes that gave rise to body subheadings of this work: Dysphagia and quality of life; Quality of Life protocols used for dysphagic patients.

## ■ LITERATURE REVIEW

### Protocols quality of life in Dysphagia

QoL protocols related to dysphagia have been used to contribute to the clinical evaluation and objective swallowing, in order to verify the patient's perception regarding swallowing disorders and the impact of it on QoL. As a complement, assists the professional speech and language therapist in preparing its conduct, monitoring of motivation for therapy, as well as it serves as a parameter to note the success of the rehabilitation process of the dysphagic subject<sup>2,12</sup>.

SWAL-QOL<sup>11</sup> protocol is an important self-assessment tool that allows elucidate the impact on QoL of the subjects resulting from the changes made at the time of feeding<sup>8</sup>. The same was translated and adapted to Brazilian Portuguese by PORTAS (2012)<sup>5</sup>, and its use enables monitoring of the rehabilitation through the patient's vision, being sensitive in identifying the dysphagic patient and the establishing of the involvement degree of swallowing regardless of etiology<sup>5</sup>.

The protocols are consisted of 44 questions covering 11 areas: swallowing as a burden, desire to feed, the feeding duration, frequency of symptoms, food selection, communication, fear of eating, mental health, social, sleep and fatigue. The questionnaire has five response options ranging from always, often, sometimes, a little or never. The score ranges from 0 to 100, where the lower the score, the greater the interference of the dysphagia patient's QoL. There are also four supplementary questions (presence or absence of feeding alternative path, the food and liquified consistency and self-assessment on health in general) that assist the course of the treatment<sup>5</sup>.

Validation of MDADI questionnaire for Brazilian Portuguese there was also a comparison with the SWAL-QOL questionnaire, so that it was done with the MDADI total and each área of SWAL-QOL. It was evidenced strong, moderate correlation and some of them with weak correlations. However, all of them were statistically significant, which demonstrates that both can evaluate the quality of life related to

swallowing, though, the MDADI be more specific for patients with head and neck cancer.

The MDADI<sup>10</sup> questionnaire was translated and adapted to Brazilian Portuguese. It consists of 20 questions, one global and the other divided into categories of emotional, functional and physical area, so it is the only one questionnaire for the assessment of the effects of dysphagia in subjects undergoing cancer treatment in head and neck. The score ranges from 0 to 100, and the lower the score, the more negative is the effect of dysphagia in QoL<sup>5,9</sup>.

But Dysphagia Handicap Index (DHI) questionnaire<sup>12</sup> consists of 25 items divided into emotional, physical, functional and one global subcategories, besides the self-assessment of the degree of difficulty in swallowing referred by the subject, which may vary from normal to severe. It evaluates the effects of dysphagia on QoL in subjects with different underlying diseases and may also be used in subjects with lower levels of education. For questionnaire validation, the final version was administered in both sexes, with different medical diagnoses, and the reliability of the test-retest for the total score and subscales was strong for DHI total and the DHI subscales.

For cultural adaptation and validation into Portuguese of Brazil, the DHI questionnaire was administered to 80 patients who underwent treatment for head and neck cancer and 105 healthy individuals, comparing the data with the SWAL-QOL questionnaire. The results showed significant coefficients in all items showing that the questionnaire is eligible and reproducible<sup>13</sup>. There were no other studies that used the questionnaire to verify the QoL associated with deglutition.

### **Use of dysphagia in quality of life protocols**

Any disturbance in the swallowing process, whether in the oral, pharyngeal or esophageal phase, features a dysphagia, which is considered a secondary manifestation of a primary pathology of neurological, systemic, infectious, mechanical or traumatic origin<sup>3,14</sup>.

The neurogenic dysphagia is a disorder in the process of swallowing resulting from a neurological or trauma disease, resulting, in most of the time, a sensory-motor impairment in the oral and / or pharyngeal stage, and may cause different impacts on QoL of the subjects<sup>2,3,15</sup>.

Mechanical dysphagia occurs in the presence of structural modifications, but the neural control remains intact. In most cases, swallowing difficulty is related to tumors of the head and neck, and the choices of treatment modalities influence significantly the severity of the changes found<sup>2,16</sup>.

Surgical treatment with or without chemotherapy and radiation therapy aims to remove the tumor and increase the survival rate of subjects, for this, the mode tends to be more aggressive, and brings the short, medium and long-term consequences, impacting so significant swallowing function and global QoL of patients<sup>9,13,17</sup>.

Chronic obstructive pulmonary disease (COPD) is a respiratory disease considered preventable and treatable, which has a significant morbidity and mortality<sup>18</sup>. Among the manifestations are related to the functions of breathing, with progressive dyspnea, swallowing, resulting in dysphagia<sup>19,20</sup>, it is considered a disabling disease that affects the quality of life of the subjects.

Regardless of the type and severity, dysphagia affects the efficiency and safety of food and is directly associated with cessation of eating pleasure, it may cause deficits in proper nutrition and hydration of the subjects, and consequently affecting the QoL of these<sup>3,14,21</sup>.

Restrictions on the food of consistency and adaptations to make swallowing safer, as the use of protective maneuvers, can bring feelings of shame, dismay and embarrassment, leading the patient to be isolated to make its meals, avoid public places and social contact<sup>2</sup>.

Evaluating the QoL associated with swallowing is important to know the real impact of the experienced changes during feeding, according to the perception of the subject and thus properly direct the management of dysphagic patients seeking a better rehabilitation of dysphagia<sup>11,22</sup>.

Study that evaluated QoL in older people after Ischemic Stroke, comparing 30 subjects with dysphagia and 30 subjects without dysphagia, found that the group without dysphagia had more pain and better general health than the group with dysphagia. The authors explain the second found result, as the absence of dysphagia after stroke in the elderly, which can lead to aspiration and consequently pneumonia, it leads to better general state of health.

However, they found no plausible explanation for the group without dysphagia presents more pain<sup>23</sup>.

Another study aimed to analyze QoL associated with swallowing of 28 patients with mechanical dysphagia (fifteen undergoing total laryngectomy and thirteen to pharyngolaryngectomy), and found as a result the impact on QoL associated with swallowing, even in cases of mild dysphagia, showing that the assessment of QoL can guide the speech and language therapy clinic through the perception of the patient, characterizing swallowing alterations after these surgical procedures<sup>24</sup>.

Authors	Sample	Methodology	Conclusions
Bandeira et al. (2008)	29 subjects after cancer treatment for tongue cancer.	Description of quality of life related to swallowing using the different areas of SWAL-QOL	Subjects with advanced disease who have undergone radiation therapy had significantly worse scores in most areas.
Plowman-Prine et al. (2009)	36 subjects with Parkinson's disease, with and without dysphagia.	Application of SWAL-QOL.	The group with dysphagia showed a significant reduction in the total score in mental health and social area.
Queija et al. (2009)	28 subjects, 15 undergoing total laryngectomy and 13 to pharyngolaryngectomy.	Application of SWAL-QOL.	The questionnaire indicated good quality of life in almost all scales. The swallowing difficulties were associated with the questionnaire in the burden and mental health scales. The questionnaire indicated impact on the mental health scale for patients with severe dysphagia.
Chen et al. (2001)	100 subjects diagnosed with cancer in the head and neck undergoing combined treatments of surgery, radiotherapy and chemotherapy.	Application of MDADI questionnaire.	Worse quality of life in patients with tumor in oral cavity and ones with malignant tumor on all items.
Xia et al. (2011)	120 subjects after stroke with dysphagia, divided randomly in three groups with the same number of subjects: conventional therapy, VitalStim® and conventional therapy associated VitalStim®.	Application of SWAL-QOL pre and post-treatment.	After treatment, the punctuations in all the groups were significantly higher compared to pre-treatment, with no statistically significant differences between groups.
Heijnen et al. (2012)	88 subjects with Parkinson's Disease divided into three groups: conventional therapy, conventional therapy associated with the electrical stimulation with applied intensities varying in the two latter groups.	Application of SWAL-QOL and MDADI protocols to check the quality of life in different groups.	In SWAL-QOL was significant improvement in the index of symptoms in all groups after treatment. In MDADI it was found significant improvement in subscales in all groups, however, there were no significant differences between groups.
Guedes et al. (2013)	72 adult subjects with head and neck cancer after surgery with or without radiation therapy.	Quality of life assessment using the MDADI protocol.	Minimum limitation in emotional and functional areas, and moderate limitation in the physical areas.
Prestwich et al. (2014)	56 subjects with oropharyngeal cancer, 43 used gastrostomy and 13 nasogastric tube.	Evaluation using MDADI before, during and after treatment of chemoradiotherapy.	There was no difference between the two feeding strategies on swallowing and the quality of life in various areas before and during treatment. Positive correlation was observed only in subjects who used the six months diet after the treatment in all areas.
Robertson et al. (2013)	147 subjects after treatment of laryngeal cancer.	He investigated the association between tumor staging and treatment modalities in the quality of life through MDADI protocol.	The worst scores were found in subjects who had more advanced tumors. There was no difference between subjects who received different types of treatments.
Shinn et al. (2013)	109 subjects with oropharyngeal cancer.	She verified adherence to speech and language therapy and quality of life related to swallowing during and after radiation treatment through MDADI protocol.	Improvement in quality of life associated with adherence to therapy.
Souza (2014)	80 subjects treated for head and neck cancer and 105 healthy individuals.	He verified the quality of life related to swallowing both groups through DHI protocol by comparing the scores of the subjects underwent surgery, radiotherapy and / or chemotherapy combine or not with healthy subjects.	The dysphagic group treated of head and neck cancer had a poorer quality of life.

Subtitle: SWAL-QOL = Quality of life in Swallowing Disorders; MDADI = MD Anderson Dysphagia Inventory; DHI = *Dysphagia Handicap Index*

### Figure 1 – Use of quality of life protocols in dysphagia

Bandeira et al., (2008)<sup>22</sup> they conducted a study with 29 patients after treatment for tongue cancer, in order to describe the quality of life related to swallowing of these, using the different areas of SWAL-QOL. They found that patients with advanced disease who have undergone radiation therapy had significantly worse scores in most areas. Aspects related with swallowing were factors that contributed to a negative impact for patients with tumors in advanced stage who underwent radiotherapy.

DHI questionnaire was administered in 80 patients who underwent treatment for head and neck cancer and 105 healthy individuals. The values of the scores of dysphagic group were higher than those in the control group values, being expected due to changes caused by treatment (surgery and / or radiotherapy and / or chemotherapy) and stressing that the questionnaire is sensitive for the studied population<sup>13</sup>.

A systematic review study aimed to identify the quality of life questionnaire in Dysphagia (SWAL-QOL) is an instrument used to assess swallowing the individual with Parkinson's disease found that there are still few studies that assess quality of life in dysphagia in parkinsonian individuals through this instrument. After the analysis of the studies, it was found that the application of this questionnaire is more effective when evaluating the result of the overall score, comparing the presence or absence of Parkinson's disease. Therefore, the use of SWAL-QOL in parkinsonian individuals may provide relevant information to the health professional about swallowing and other manifestations due to changes in this function, which should be a factor to be decisive in the choice of treatment procedures<sup>25</sup>.

The study of Plowman-Prine et al. (2009)<sup>25</sup> with parkinsonian patients found that QoL in dysphagia is highly correlated with the overall quality of life in health and the SWAL-QOL may indicate an understanding of the overall quality of life of parkinsonian individual. In addition, the same authors reported that the current literature is geared to the physiological aspects of swallowing in Parkinson's disease, and the SWAL-QOL is an effective and important tool for clinicians consider the manifestations of dysphagia, especially on the psychosocial functioning of the individual with Parkinson's disease.

Xia, Zheng, Law et al. (2011)<sup>26</sup> used the SWAL-QOL protocol to investigate the effects of conventional therapy and neuromuscular electrical stimulation (VitalStim®) in subjects with dysphagia after stroke, and they are divided into three groups: conventional therapy, VitalStim® and conventional therapy associated VitalStim®. They found that after treatment the SWAL-QOL scores in all groups were significantly higher compared to pre-treatment, with

no statistically significant differences between the groups, suggesting that different therapy modalities have improved swallowing function in post-stroke patients with reflection in improvement of QoL.

The study of Heijnen, Speyer, Baijens, et al. (2012)<sup>27</sup> aimed to investigate the effects of neuromuscular electrical stimulation (VitalStim®) compared with conventional therapy for dysphagia in subjects with Parkinson's disease (PD) also using the SWAL-QOL and MDADI protocols to check QoL. The participants were 88 subjects with PD who were divided into three groups, with one group (conventional therapy), group two and three (conventional therapy associated with electrical stimulation with applied intensities varying in these groups). In SWAL-QOL was only significant improvement in the index of symptoms in all groups after treatment. In MDADI was found significant improvement in subscales in all groups, however, there were no significant differences between groups.

Cassol, Galli, Zamberlan et al. (2012)<sup>8</sup> used the SWAL-QOL to assess QoL in healthy elderly swallowing relating the rates obtained with the variables age, sex, socioeconomic status and use / adaptation of dental prosthesis. They found that, in general, older people are not self-reported significant changes to the QoL in swallowing and they that possibly swallowing difficulties are most frequent when there is underlying pathology associated.

The work of Chen et al. (2001)<sup>10</sup> evaluated 100 patients diagnosed with cancer in the head and neck, especially of the larynx, undergoing combined treatments of surgery, radiotherapy and chemotherapy applying the MDADI questionnaire. It has been found worse QoL in patients with tumor in oral cavity and with malignancy in all items, and the statistically significant values.

Guedes work, Carrara-Angelis, Chen et al. (2013)<sup>9</sup> aimed to adapt and validate the MDADI protocol for Brazilian Portuguese and evaluate the QoL associated with dysphagia in 72 subjects with head and neck cancer who underwent surgery with or without radiation therapy in a referral hospital for this disease. They found as a results minimum limitation in emotional and functional areas, and moderate limitation in the physical area.

The worst values were seen in subjects with advanced tumors, and the presence of metastasis was significantly associated with worsening of the values in all the individual areas and global scores of MDADI. The authors also point out that the subjects who used a feeding alternative path, the score was very low compared to the rest of the group, a fact that confirms the decrease in QoL associated with dysphagia, mainly by social isolation at meal time.

Prestwich et al. (2014)<sup>28</sup> analyzed the impact on swallowing function after performing chemoradiotherapy in 63 subjects with oropharyngeal cancer and compared two strategies of enteral nutrition (nasogastric and gastrostomy tube), before, during and after treatment, using MDADI to check QoL. Of the total, only 56 subjects answered the questionnaire, and 43 (77%) used gastrostomy and 13 (23%) nasogastric tube. It was found that there was no statistically significant difference between the two feeding strategies on swallowing and QoL in the different areas before and during treatment. A positive correlation was observed only in subjects who used only the six months diet after treatment in all areas, which demonstrates the important influence that food restriction orally brings to life of the subjects.

Robertson's research, Yeo, Sabey et al. (2013)<sup>29</sup> investigated the association between tumor staging and treatment modalities in the functional results of swallowing and the quality of life of individuals with laryngeal cancer, through MDADI QOL protocol. 147 subjects participated, they demonstrated that the median total score was 78 (range 0-100), with significant differences between the median of scores of patients according to tumor staging, with the lowest scores were found in those had more advanced tumors. It is evident that the more comprehensive the tumor is and more structures are achieved, more invasive treatments will be with worsening swallowing function and consequent influence on quality of life.

The study of Shinn, Basen-Engquist, Baum et al. (2013)<sup>17</sup> found adherence to speech and language therapy and the QoL related to swallowing in subjects diagnosed with oropharyngeal cancer during and after radiation treatment using MDADI protocol. They met results in the improvement of QoL was significantly associated with adherence to speech and language therapy, in other words, subjects who

properly held the speech exercises for swallowing showed better QoL. Otherwise, smaller values were found in participants who did not adhere to therapy, the conclusion was that the difficulty in swallowing remained after treatment, influencing negatively the QoL of the subjects.

The literature findings emphasize the need to use QoL protocols associated with swallowing in speech and language therapy clinical practice, since studies have shown the negative influence that the change of swallowing function carries on QoL of the subjects, especially with regard to social isolation the need to adapt the way of eating.

## ■ CONCLUSION

Dysphagia is a symptom of various underlying diseases and its manifestation significantly affects negatively the QoL of the subjects. For the assessment of QoL the literature proposes three protocols, and the most used to assess QoL in general, QoL related to head and neck cancer and QoL of subjects with different medical diagnoses.

The use of these protocols is not yet widespread in daily speech therapy practice with dysphagic patients, although there is a growing interest, as they can help and complement the clinical and objective evaluation of swallowing, since, they portray the self-assessment referred to the subject, and this view is extremely important for speech and language therapy.

QoL questionnaires can be used to check the effects of various treatments, help speech and language therapy conduct, monitoring of adherence to therapy, as well as to verify the success of the rehabilitation process of dysphagic subject.

**RESUMO**

O objetivo deste estudo foi identificar os protocolos existentes sobre qualidade de vida (QV) em disfagia e verificar a utilização dos mesmos no tratamento fonoaudiológico. Realizou-se pesquisa teórica e exploratória com a técnica de revisão da literatura nas bases de dados SCOPUS, Trip Database, LILACS, PubMed, SciELO, Google Scholar, periódicos Capes e MedLine. O período de busca compreendeu os anos entre 2004 e 2014 e foram utilizados os seguintes descritores: deglutição; transtornos da deglutição; qualidade de vida; questionários e os seus respectivos termos em inglês *deglutition; deglutition disorders; quality of Life; questionnaires*. Foram encontrados na literatura o protocolo Quality of life in Swallowing Disorders-SWAL-QOL, o qual estabelece o comprometimento da deglutição independente da etiologia; o MD Anderson Dysphagia Inventory, que é específico para sujeitos submetidos à tratamento de câncer de cabeça e pescoço e o Dysphagia Handicap Index, que avalia os efeitos da disfagia sobre a qualidade de vida (QV) em sujeitos com diferentes patologias de base e pode ser utilizado em níveis mais baixos de escolaridade. A literatura propõe diferentes protocolos que avaliam a QV em disfagia, sendo que os mais utilizados avaliam a QV de forma geral, relacionada ao câncer de cabeça e pescoço e de sujeitos com diferentes diagnósticos médicos. A utilização desses protocolos pode auxiliar e complementar a avaliação clínica e objetiva da deglutição, uma vez que, retratam a autoavaliação referida pelo sujeito, sendo este ponto de vista de extrema importância para o tratamento fonoaudiológico.

**DESCRITORES:** Deglutição; Transtornos da Deglutição; Qualidade de Vida; Questionários

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