Original

Cross-Cultural Adaptation of the SWAL-QOL and Swal-Care Questionnaires into Brazilian Portuguese

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Abstract:

The translation and cross-cultural adaptation was performed on the English-language SWAL-QOL and SWAL-CARE questionnaires to a Brazilian Portuguese version. The translation and cross-cultural adaptation was performed following accepted international guidelines. Stage I was the translation of the English questionnaires to Brazilian Portuguese by two bilingual health professionals. Stage II involved the back-translation produced by a native-speaking English bilingual speaker of the original language. Stage III was the revision of the translated and original version by a bilingual multiprofessional expert committee with experience in dysphagia. Stage IV involved a field test to check the cultural equivalence between the two versions. They were applied in 22 dysphasic patients treated for head and neck cancer. After the first 10 prefinal version applications (Phase 1) the responses were analyzed by expert committee and then necessary adaptations for Brazilian population and culture were carried out. This revised prefinal version was then field tested in 12 more patients (Phase 2) and reanalyzed with the modifications to reach the final version. There were no significant divergences between the translation and back-translation. The translated version of the two questionnaires applied in Phase 1 (10 patients) showed two not applicable items in the general advice domain of the SWAL-CARE questionnaire and 12 not applicable items in the SWAL–QOL questionnaire distributed within its domains. These questions were then modified and adaptations with semantic, conceptual, idiomatic and experimental equivalences were done. Not applicable items were not identified in Phase 2. The SWAL-CARE and SWAL-QOL questionnaires were translated to Brazilian-Portuguese and adapted to the Brazilian culture.

Keywords: Quality of life; Questionnaire; Deglutition disorder

Introduction

The evaluation of the quality of life of the chronically ill is a constant preoccupation from the beginning of medical history until the present.[1-2] The interest for the subject has been gaining more and more importance in the scientific context due to countless forms of illness treatments that promote cure and increase survival rate, creating the necessary to know which kinds of treatment provide the best quality of life for patients.

According to Andrade,[3] the quality of life concept is formed by a set of possible values, which make the establishment of relevant and irrelevant aspects for each individual difficult, leading to a lower consensus of opinion. As such, it is difficult to reach the common concept on the definition of quality of life.

The World Health Organization defines quality of life as an individual perception of the position of the subject in life, in the context of their culture and value system in which they are within and in relation to their objectives, expectations, standards and preoccupations.

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It is a concept of comprehensive reach affected in the complex form by physical health, psychological state, independence level, social relations and relationship with the characteristics of the environment they are within.[4]

Various quality of life questionnaires, generic and specific, with a majority in foreign languages, can be found in the literature. They attempt to recognize the quality of life of individuals in different situations, and from this intercession to improve, always when necessary, or prioritize determined types of conduct. In other words, to objectively evaluate the focus of the patient, their prognosis, therapeutic impact and the distinction between patient and groups of patients, in addition to comparing therapeutic interventions with similar cure rates.[2]

However, the use of these instruments in another language that is not the original of its construction needs the translation and adaptation for the new population to which it is destined, following internationally accepted norms, so that the original questionnaire and its content do not acquire modifications that affect its interpretation and scientific value, and consequently can be comparable between cultures.[5-6]

Information on the quality of life related to deglutition are fundamental in order to know the true impact of alterations experienced in the moment of feeding and direct the treatment and the commitment of health professionals as to the aspects that contribute for a better dysphagia rehabilitation.[7-10]

Any alteration in the process of deglutition that should obstruct a safe, efficient and comfortable oral ingestion is defined as dysphagia. This symptom can cause clinical risk of dehydration, malnutrition, aspiration of foods, leading to pneumonia and/or serious pulmonary disturbances and compromising the quality of life in the personal, social and familiar aspects.[11]

With the intention of evaluating the quality of life specifically related to dysphagia, the questionnaires Quality of Life in Swallowing Disorders (SWAL-QOL) and Quality of Care and Patient Satisfaction (SWAL-CARE) by McHorney et al. [12-14] were constructed.

The SWAL-QOL has scales developed to differentiate individuals with normal deglutition and patients with oropharynge dysphagia of different etiologies, also being sensitive to clinically differentiate the gravity of the same. The SWAL-CARE aims to know the quality of the care with deglutition and patient satisfaction in relation to orientation received.[12-14]

In Brazil, some generic questionnaires (EORTC C30, SF 36) and disease-specific (UW-QOL) were validated for Brazilian Portuguese. However, these possess only 3 to 5 comprehensive questions in the domains referring to deglutition and do not serve to evaluate the quality of life related to deglutition.[10] In the Brazilian Portuguese language, no questionnaire was found directed to the evaluation of the quality of life in relation to deglutition.

Therefore, the objective of the present study is to carry out the cross-cultural translation and adaptation of the SWAL-QOL and SWAL-CARE questionnaires to Brazilian Portuguese. It is worth stressing that a psychometric validation is necessary to use these instruments in Brazil, which will be carried out subsequently.

Materials and Methods

The cross-cultural translation and adaptation from English to Brazilian Portuguese of the SWAL-QOL and SWAL-CARE questionnaires was authorized by McHorney and collaborators, the authors of the original. The cross-cultural translation and adaptation stages followed were proposed by Peters and Passchier.[15] These authors carried out a revision of the different existent guidelines in the literature, between them, the proposed Medical Outcomes Trust, Guillemin et al., Hilton and Skrutowski and Meadows, resulting in their proposal of "recommendations for a high-quality translation.

The first stage of the cross-cultural adaptation process began with the translation of the questionnaires in English (source language) to Brazilian Portuguese (target language) by two bilingual translators of the health profession (speech-language pathologists). They were instructed with the conceptual translation of the questionnaires, avoiding literal translation. The translations were compared, reaching a final version with content preserved.

In the second stage, this final version was then back translated by a bilingual of the original language (English) looking to reveal faults in the adaptation of the context for the culture-target and ambiguity of the original version.

In the third stage, a revision of the original version and of the version translated by an expert committee formed by three bilingual health professionals with experience in dysphagia was carried out. The function of the expert committee was to verify the cross-cultural equivalence of the original and translated versions in semantic, idiomatic, experimental and conceptual aspects.

To check the equivalence between the two versions, original and translated, a field test was carried out

(fourth stage) with the application of the questionnaires in 22 patients with existent dysphagia treated for cancer of the head and neck by the Department of Head and Neck and Otorhinolaryngology Surgery of Hospital A.C. Camargo and by the Speech-Language Pathology Department of the same institution. For each of the questions, the alternatives were increased with the option "not applicable" for the identification of questions not understood or not appropriate for the population, which would be considered invalid for the culture in question.

After the first 10 applications (Phase 1) the responses were analyzed by the expert committee composed by professionals with experience in the rehabilitation of the population in study, in which necessary adaptations were carried out for the Brazilian population and culture. The percentage of 30% to the answer "not applicable" for each item in question was considered as criteria for the modification of questions.

This prefinal version, with the proper modifications, was then applied in 12 more patients (Phase 2), and re-analyzed to reach the final version.

The inclusion criteria for the application of these questionnaires were: adult individuals; independent of gender; treated for cancer of the head and neck; with existent dysphagia in the last month for the application of the SWAL-QOL, since its questions revolve around the difficulties experienced in this period. Patients in speech-language therapy treatment with a minimum of two therapy sessions were also included for the application of the SWAL-CARE questionnaire, since this is treated as a questionnaire that includes aspects revolving around speech-language therapy orientation and rehabilitation. Excluded were patients who presented a history of neurologic pathologies associated with a deficit in comprehension and/or communication expression, with total laryngectomy and patients who refused to participate in the study.

Individual interviews were scheduled according to patient availability or on the day of speech-language therapy itself. The signature of free and informed consent was solicited.

The questionnaires were applied by two properly trained speech-language pathologists, observing the criteria of no prior contact between the patient and therapist.

The SWAL-QOL questionnaire is composed of 10 domains (burden, eating duration, eating desire, frequency of symptoms, food selection, communication, fear, mental health, social function, sleep and fatigue) and the responses vary from 1 to 5, while the SWAL-CARE is composed of 3 domains (clinical information, general advise and patient satisfaction) and the responses vary with scores of 1 to 6.

Results

In the stages of translation, back translation and revision of the version translated with original, there were no significant divergences of the SWAL-QOL and SWAL-CARE questionnaires, in spite of grammatical and cultural differences between the Brazilian and American populations.

Participating in the field test (fourth stage), were twenty-two patients (14 male and 8 female) with an average age of 59 years. Principal characteristics of the population: elementary-level education (table1); oral cavity as lesion site; subjected to surgery associated with adjuvant radiotherapy as elective treatment; and pelveglossomandibulectomy as the most frequent type of surgery (table 2). All patients had the diagnosis of dysphagia in process of rehabilitation by the speech-language pathology department.

Table 1 – Distribution of field test characteristics (n=22), in accordance with demographic variables.

Variable	Category	n(%)Measures
Sex	Male	14 (63.6)
	Female	8 (36.3)
Race	White	19 (86.3)
	Black	3 (13.6)
	Asian	0 (0)
Age(years)	Min-Max	25-82
	Median	59
	Avg SD±	59.7±12.4
Education	Elementary	12 (54.5)
	High School	5(22.7)
	Superior	5 (22.7)
Marital Status	Single	2 (9.0)
	Married	11 (50)
	Widowed	3 (13.6)
	Divorced	6 (27.2

In Phase 1 of the field test, two not applicable items in the general advise domain of the SWAL-CARE questionnaire were evidenced where semantic

Table 2 – Distribution of field test characteristics (n=22), in accordance with clinical characteristics and treatment.

Variable	Category	n(%) Measures
Lesion Site	Oral Cavity	13 (59)
	Oropharynge	3 (13.6)
	Larynge	4 (18.1)
	Others	2 (9.0)
Surgery Type	Partial glossectomy	1 (4.5)
	Total glossectomy	1 (4.5)
	Pelveglossomandibulectomy	8 (36.3)
	Partial Pelveglossectomy	2 (9.0)
	Horizontal supraglottic laryngectomy	1 (4.5)
	Palatectomy	1 (4.5)
	Maxillectomy	1 (4.5)
Treatment undergone	Surgery	6 (27.2)
	Surgery+adjuvant radio-therapy	8 (36.3)
	Surgery + radiotherapy + chemotherapy	1 (4.5)
	Radiotherapy +chemo-therapy	5 (22.7)
	Radiotherapy exclusive	2 (9.0)

changes in the negative sentences for affirmatives, since there was a great difficulty of understanding of the same, as for example: "I never know when I am going to choke" was substituted for "knowing when I am going to choke is very difficult." Additionally, experimental and conceptual equivalences were carried out due to differences in the food habits between the Brazilian and American populations, where apricot nectar and milkshake are not everyday drinks in the Brazilian population, principally in those of low income (Table 3).

In Phase 2 of the field test, with proper modifications and adaptations made, not applicable items were not identified with significant incidence for changes, reaching the final version in Brazilian Portuguese of the instruments in study.

Discussion

With technical-scientific developments, the health sciences have been trying to author effective questions in relation to the quality of life for patients. Therefore, a myriad of instruments for measuring such questions have been structured, developed, consolidated and applied to a good part of this population.[16]

The questionnaires, while evaluating the patient individually, elucidate the aspects that are not routinely evaluated by the professional and are not exposed by the patient (depression, sexual activity, anxiety, facing of the disease), identifying aspects that should be worked with greater emphasis.[2]

Due to the existence of so many instruments, the definition of what to be investigated for the choice of the most appropriate questionnaire becomes essential. Generally, the principal characteristics to be observed in the choice of the questionnaire are: validation; viability; acceptability; reliability; sensibility; ease of understanding

Table 2 – Number and percentage of patients that identified not applicable items in Phase 1 of the field test of the SWAL-CARE questionnaire, in each domain, modifications made and type of cultural equivalence

Domains	Not applicable items	n (%) patients	Modifications / adaptations	Cultural Equivalence
Clinical information	-	2	-	
General Advice	When I should contact a speech-language pathologist	4	When I should procure a speech-language pathologist	Semantic
	Signs that I am not getting enough to eat or drink	3	When I know that eating and drinking is not safe or efficient	Semantic Idiomatic
Patient satisfaction		1		

equivalences were carried out with word substitutions with the same meaning but more popular to better facilitate understanding of the questions.(Table 3)

In the SWAL-QOL questionnaire, twelve not applicable items were noted in the domains burden, eating desire, food selection, fear, mental health, social function, sleep, liquid consistency and food texture. In these domains, semantic equivalences were carried out with

Table 3: Number and percentage of patients that identified not applicable items in Phase 1 of the field test of the SWAL-QOL questionnaire, in each domain, modifications made and type of cultural equivalence

Variable	Not applicable items	n (%) patients	Modifications / adaptations	Cultural Equivalence
Burden	Alternatives (very true, quite a bit true, somewhat true, a little true, not at all true	4	Alternatives (always, many times, sometimes, a little, never)	Semantic
Eating duration	—	—	—	—
Eating desire	On most days, I don´t care if I eat or not	4	On most days, I feel whatever if I eat or not	Semantic
	I don´t enjoy eating anymore		I eat without feeling pleasure	
Symptom frequency	2 items	3	—	Semantic
Food selection	Alternatives (strongly agree, agree, uncertain, disagree, strongly disagree)	4	Alternatives (totally agree, partially agree, I don´t know, partially disagree, totally disagree	—
Communication	2 items	2	—	Semantic
Fear	Never know when I will choke	3	To know when I will choke is very difficult	
Mental health	Alternatives (always true, almost always true, sometimes true, hardly ever true, never true)	4	Alternatives (always, almost always, sometimes, hardly ever, never)	Semantic
Social function	I don´t eat out due to my swallowing problem	3	I stopped going out to eat due to my swallowing problem	Semantic
Sleep	Have trouble staying asleep?	3	Sleep the entire night?	Semantic
Liquid consistency	You ingest slightly thick liquids as tomato juice or apricot nectar	5	You ingest slightly thick liquids as tomato juice or yogurt	Experimental / Conceptual
	You ingest moderately thick liquids, like milkshakes. This type of liquid is difficult to suck through a straw, as a very thick milkshake	3	You ingest moderately thick liquids, like smoothies. This type of liquid is difficult to suck through a straw, as a very thick smoothie	Experimental / Conceptual
	You do not ingest liquids by the mouth or have been limited to crushed ice	3	You do not ingest liquids by the mouth.	Experiental/ Conceptual
Food Texture	You are eating soft, easy to chew foods as casserole, canned fruits, steamed vegetables, roots and creamy soups	7	You are eating soft, easy to chew foods as stews, canned fruits, steamed vegetables and creamy soups	Experimental / Conceptual

for the patient; minimize opportunities of bias attributed to an investigator; and the lowest possible cost for the institution.[17]

Guillemin et al.[5] emphasizes that most of the questionnaires are developed in English speaking countries and that even inside these countries the investigators must consider the immigrant populations in their studies, since this variable could lead to a systematic polarization in treatment or quality of life studies.

To date, the necessity is recognized of not only translating the questionnaires correctly, but also to promote cultural adaptation so that the content of the instrument is valid and is maintained in its cultural level.[18]

The attention at this level of detail permits the increase of confidence in disease impact or treatment and allows a similar description in multinational studies and in the evaluation of the results.[19-20]

For the adaptation process, a complete and planned description of the cultural equivalences is made necessary in order to maximize the semantic, idiomatic, experimental and conceptual relations between the different cultures.[6]

Beaton[6] defines the use of experimental equivalence as the translation of the habits of the daily life of a determined culture, as an example, in Brazil, there is the tradition of using silverware for meals, while

in Japan, it is chopsticks. Conceptual equivalence is to discern the concept of each word for different cultures, in other words, the concept of family in Brazil can be different from that of the Japanese population. The idiomatic equivalence is the translation of idiomatic expressions of a determined culture and semantic equivalences are used to equate grammatical difficulties that have the same meaning.

The equivalence most encountered in this study was semantic, which can be understood by the low degree of education of the studied population, which corroborates with Brazilian reality, where a great part of the population has no access to education. We believe in this hypothesis due to the semantic equivalences not having been carried out by difficulty in grammar or the significance of the words, but ignorance of the Brazilian Portuguese language.

Sentences with "double negatives" were another difficulty encountered in the adaptation process, as they were modified to the affirmative form for better understanding. The same difficulties were observed in the study of Sousa[1] of the validation of the Hospital Saint George respiratory disease questionnaire (SGRQ).

When the questionnaires were subjected to field test with the Brazilian population, divergences of the habits of daily life regarding food were shown. It was opted to exclude part of the sentence "You do not ingest liquids by the mouth *or have been limited to crushed ice*" because it is not part of our habits and culture to offer crushed ice for patients with restriction of liquids.

All the equivalences carried out in the SWAL-QOL and SWAL-CARE questionnaires did not compromise the validity of the original instrument, since its content and objective were preserved. Once translated and adapted, this final version must be subjected to stages of psychometric validation.

Conclusion

The SWAL-QOL and SWAL-CARE questionnaires were translated to Brazilian Portuguese and adapted for the Brazilian population, maintaining the objective and content of the original version.

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