



FACE-Q Head and Neck Cancer Questionnaire for Brazilian Portuguese: Translation, Cross-Cultural Adaptation, and Linguistic Validation

Tradução, adaptação e validação linguística do FACE-Q Câncer de Cabeça e Pescoço para o português do Brasil

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■ ABSTRACT

Introduction: Head and neck neoplasms often affect fundamental functions, such as swallowing, speech, eating, and socializing. Evaluating their treatment should consider the physician's opinion and the patient's perspective. This difficulty in assessing the success of treatment led to the development of the FACE-Q Head and Neck Cancer Module, a questionnaire of patient-reported outcomes that measure the appearance, facial function, quality of life, and experience of care to head and neck neoplasms. The objective is to translation, cultural adaptation, and linguistic validation of the FACE-Q Head and Neck Cancer questionnaire for Brazilian Portuguese. **Methods:** The translation, cultural adaptation, and linguistic validation of the full questionnaire took place in four stages, using official guidelines from the World Health Organization and the International Society of Pharmacoeconomics and Outcomes Research. **Results:** A semantic, idiomatic, and conceptually equivalent Brazilian Portuguese version was achieved through a linguistically validated translation of the English FACE-Q Head and Neck Cancer module. **Conclusion:** The Brazilian Portuguese version presents a version equivalent to the original English instrument, which can be used as a critical patient-reported outcome assessment. **Keywords:** Head and neck neoplasms; Reconstructive surgical procedures; Quality of life; Patient outcome assessment; Outcome assessment, health care.

■ RESUMO

Introdução: As neoplasias de cabeça e pescoço costumam afetar funções fundamentais, como engolir, falar, comer e se socializar. A avaliação do seu tratamento deve, portanto, levar em consideração a opinião do médico e a perspectiva do paciente. Essa dificuldade em avaliar o sucesso do tratamento levou ao desenvolvimento do FACE-Q - Módulo de Câncer de Cabeça e Pescoço, um questionário de resultados relatados pelo paciente que mede a aparência, função facial, qualidade de vida e experiência de cuidado para neoplasias de cabeça e pescoço. O objetivo é a tradução, adaptação cultural e validação linguística do questionário FACE-Q Câncer de Cabeça e Pescoço para o português brasileiro. **Métodos:** A tradução, adaptação cultural e validação linguística do questionário completo ocorreram em quatro etapas, usando as diretrizes oficiais da Organização Mundial da Saúde e da Sociedade Internacional de Farmacoeconomia e Pesquisa de Resultados. **Resultados:** Uma versão em português brasileiro semântica, idiomática e conceitualmente equivalente foi obtida por meio de uma tradução validada linguisticamente do módulo FACE-Q Head and Neck Cancer em inglês. **Conclusão:** A versão em português brasileiro apresenta uma versão com equivalente ao instrumento original em inglês, que pode ser utilizada como avaliação crítica de resultados relatados pelo paciente. **Descritores:** Neoplasias de cabeça e pescoço; Procedimentos cirúrgicos reconstrutivos; Qualidade de vida; Avaliação de resultados da assistência ao paciente; Avaliação de resultados em cuidados de saúde.

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INTRODUCTION

Head and neck neoplasms have a high incidence and represent significant morbidity and mortality, as they often affect fundamental functions, such as swallowing, speech, eating and socialization^{1,2}. The treatment of this pathology may involve multiple modalities, such as chemotherapy, radiotherapy and surgery, with varied involvement of these functions over time and often with the need for complex reconstruction processes³.

Therefore, evaluating the results of these procedures should consider the physician’s opinion and the patient’s perspective⁴. At the same time, evidence-based medicine has led to validated instruments that compare results from different authors.

This difficulty in assessing treatment success led to the development of the FACE-Q Head and Neck Cancer Module, a patient-reported outcome questionnaire (PRO - *patient-reported outcome*) that measures appearance, facial function, quality of life and experience of care for head and neck neoplasms⁵⁻⁷. The questionnaire divides the assessment into General Appearance of the Face, Eating and Drinking, Oral Competence, Salivation, Smiling, Talking, Swallowing, Appearance Distress, Cancer Concern, Drooling Distress, Food Distress, Smiling Distress, Talking Distress, and Information (Chart 1).

Due to linguistic and cultural differences between the English-speaking population of the FACE-Q Head and Neck Cancer Module and the Brazilian population, translation, cultural adaptation, and linguistic validation of the questionnaire are essential to evaluate patients undergoing treatment for head and neck cancer in Brazil.

OBJECTIVE

The aim of this study was the translation, cultural adaptation and linguistic validation of the FACE-Q Head and Neck Cancer questionnaire into Brazilian Portuguese.

METHODS

This study was approved and authorized by the Q-Portfolio team and the association that manages its academic and commercial distribution.

Chart 1. FACE-Q head and neck cancer domains and scales.

Appearance	Facial Function	Quality of life	Care Experience
General Face	Eating and Drinking	Appearance Affliction	Information
	Oral Competence	Cancer Concern	
	Salivation	Worry about drooling	
	Smile	Affliction to eat	
	Speak	Affliction to smile	
	Swallow	Affliction to speak	

Participants were selected by convenience at the Cancer Institute of the State of São Paulo (ICESP) under approval by the Research Ethics Committee (CAE 34797120.6.0000.0068) and provided written informed consent. This study followed all procedures following the ethical standards of the institutional review board and the 1964 Declaration of Helsinki and its later amendments.

FACE-Q Head and Neck Cancer: The Questionnaire

The FACE-Q Head and Neck Cancer is a PRO (patient-reported outcome) questionnaire applied in the clinical or research environment to collect patient responses directly. It quantifies aspects of quality of life and outcome variables from the patient’s perspective, such as satisfaction, symptoms and adverse effects. PRO instruments are a way of quantifying how patients perceive their health and the impact of procedures on their quality of life⁸.

The entire instrument consists of 164 items, divided into 14 scales within four conceptual frameworks: Appearance, Facial Function, Quality of Life and Care Experience (Chart 1).

Stages of translation, cross-cultural adaptation and linguistic validation

The translation, cultural adaptation and linguistic validation of the complete questionnaire took place in four stages (Figure 1) from July 2020 to September 2020, following recommended practices^{9,10}. After each step, a report was produced, highlighting the process, the difficulties encountered, and the solutions implemented.

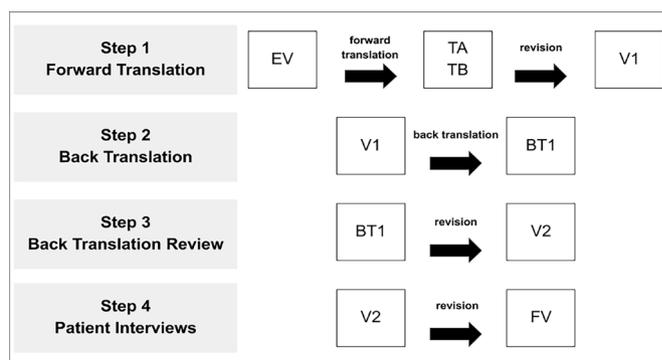


Figure 1. Stages of translation, cultural adaptation and linguistic validation of the FACE-Q Head and Neck Cancer questionnaire.

The focus of the authors, as well as the translators, was to maintain equivalence⁹:

- Semantic equivalence: check if the translated words have the same meaning.
- Idiom equivalence: formulate equivalent expressions in the target version, avoiding difficulties related to the translation of colloquialisms and idiomatic expressions.
- Empirical equivalence: replacing questionnaire words with other similar terms used in our home culture.
- Conceptual equivalence: observing whether words have different meanings across cultures, replacing inappropriate terms.

Step 1: Direct Translation

The questionnaire was translated from English into Brazilian Portuguese by two independent translators, native speakers of Portuguese and fluent in English; both had experience in healthcare translation.

Translators were instructed to translate using consistent and straightforward terminology rather than literal translations and were encouraged to provide feedback on their difficulties. At the end of the process, two versions were produced: translation A (TA) and translation B (TB)¹⁰.

The two translations were analyzed by three of the project's authors and reconciled into a consensus version in Portuguese (V1) based on elements of the two initial versions.

Step 2: Reverse Translation

In the back-translation stage, V1 was translated from Portuguese back into English by a third native American English translator, fluent in Brazilian Portuguese and with experience in the healthcare field. This process generated the reverse translation (BT) version.

Step 3: Review the Reverse Translation

The authors and one of the developers of the original questionnaire compared the original English version (EV) with BT to identify possible semantic differences between the two versions. This step produced some changes in V1 and generated a second version in Portuguese (V2).

Step 4: Interviews with Patients

Version V2 was used for cognitive interviewing and debriefing in ten patients (convenience sample) undergoing surgical treatment for head and neck cancer and native speakers of Brazilian Portuguese:

Cognitive interview: individual interviews were conducted to assess the patient's understanding of the questionnaire and confirm their interpretation of each question.

Debriefing: During the interview, each item in which the patient expressed doubts about the question or the answer was reviewed. These items were noted as well as the patients' suggestions for more understandable terms within the context of the question.

The authors evaluated all the items that generated doubts among the patients and their suggestions. All changes were reviewed for wording and agreement by a native Portuguese-speaking editor with proficiency in English to eliminate any spelling errors and align possible errors in the agreement. The authors reviewed the adjustments and produced the final version (VF).

RESULTS

Two professional translators with knowledge in the health area performed the first stage of the translation process (Direct Translation). No difficulties in understanding the original questionnaire were reported during the process. The TA and TB versions were reconciled, preserving semantic, idiomatic, empirical and conceptual equivalence. This process showed a discrepancy in 80 of the 164 items (48.8%) in the original questionnaire (Table 1). AT was maintained on 72 occasions (90%) in the conciliation process between the versions, while TB was maintained on five (6.3%). An intermediate solution was necessary on three occasions (3.8%). After this reconciliation between the TA and TB versions, V1 was defined. In this version, colloquial language was used that was easy to understand by the target audience.

As an example of a discrepancy, in the translation of the original item "Eu tenho dificuldades para me alimentar por causa da minha boca seca", both TA ("Eu tenho dificuldades para me alimentar por causa da minha boca seca.") and TB ("Tenho problemas para comer devido a minha boca seca.") were created. In this case, AT was chosen due to the greater ease of understanding. In another item ("I have a problem being understood when speaking face-to-face.") the TA version ("Eu tenho problemas para ser compreendido quando falo cara a cara") and TB ("Tenho problemas para ser entendido quando falo cara a cara") were merged to form the final option ("Eu tenho problemas para ser compreendido/entendido quando falo cara a cara.")

In the second stage of the translation process (Reverse Translation), version V1 was back-translated into English by another professional translator whose native language was English, giving rise to the BT version.

Table 1. Conciliation process between translation A and translation B.

Scales	Total number of items	Total different items	Maintained TA	Maintained TB	New/mixed solution
General Face	15	6	4	2	0
Eat and drink	12	4	4	0	0
Oral Competence	9	5	5	0	0
Salivation	12	7	7	0	0
Smile	11	3	2	0	1
Speak	11	5	4	0	1
Deglutition	12	6	4	2	0
Affliction with appearance	11	3	3	0	0
Affliction to eat	11	9	9	0	0
Drooling affliction	10	8	8	0	0
Affliction to smile	9	3	3	0	0
Affliction to speak	13	8	8	0	0
Cancer concern	13	7	7	0	0
Information	15	6	4	1	1
Total (%)	164 (100%)	80 (48.8%)	72 (90%)	5 (6.3%)	3 (3.8%)

TA: translation version A; TB: translation version B.

In the third step (Reverse Translation Review), the Q-Portfolio team reviewed the BT version to identify errors in comprehension, translation or lack of precision concerning the original version (EV). Among the 164 items present in the questionnaire, 56 (34.1%) showed exact correspondence with the original version (EV), while 108 (65.9%) showed small textual variations (Table 2). However, all these items kept their original meaning, and revisions were unnecessary. Therefore, version V1 was left unchanged at this stage, producing version V2.

As an example of the differences found between the EV and BT versions, the item “I have a problem drinking from a cup.” (EV) originated from the version “Tenho problemas para beber de um copo.” (BT), and also the item “I cannot communicate emotions with my smile.” (EV), which gave rise to the version “Não consigo demonstrar emoções com meu sorriso.” (BT).

Finally, in the fourth stage (Patient Interviews), individual interviews were carried out with ten patients who underwent head and neck cancer treatment to assess possible difficulties in understanding and confirming the correct interpretation of all items. Four patients were female, and six were male. The age range of these patients ranged from 57 to 87 years, with a median of 69 years. As for the histological type, seven patients had squamous cell carcinoma, and the others had mucoepidermoid carcinoma, basal cell carcinoma and osteosarcoma. Finally, regarding the location of the tumors, the affected regions were the forehead, orbit, maxilla (2), the mandible (2), tongue (2), lower lip and salivary gland. All questions, alternatives and suggestions resulting from this process were evaluated. Among the 164 items, 21 alterations were suggested by the patients (12.8%) to facilitate the understanding of the questionnaire items (Table 3).

Table 2. Conciliation process between the English version and the back-translation

Scales	Total number of items	Total of different items	Need for review
General Face	15	8	0
Eat and drink	12	10	0
Oral Competence	9	3	0
Salivation	12	7	0
Smile	11	5	0
Speak	11	9	0
Deglutition	12	4	0
Appearance Affliction	11	9	0
Affliction to eat	11	10	0
Drooling affliction	10	6	0
Affliction to smile	9	6	0
Affliction to speak	13	10	0
Cancer concern	13	10	0
Information	15	11	0
Total (%)	164 (100%)	108 (65.9%)	0

As an example of this last step, the original item “My face looks unattractive” originated the version “Meu rosto parece pouco atraente.” (V2), which, after the interview with the patients, was changed to “Meu rosto não parece atraente,” due to the greater adequacy of the terms used. In another example, the original version “I get frustrated when I speak” gave rise to the version “Eu me sinto frustrado quando falo”. (V2), which, after the interview with the patients, was changed to “Eu me sinto frustrado/chateado quando falo” due to the difficulty in understanding the word “frustrado.”

Table 3. Conciliation process between V2 and the final version.

Scales	Total number of items	Need for review
General Face	15	2
Eat and drink	12	6
Oral Competence	9	1
Salivation	12	2
Smile	11	2
Speak	11	2
Deglutition	12	1
Affliction with Appearance	11	0
Affliction to eat	11	0
Drooling affliction	10	0
Affliction for Smiling	9	0
Affliction to speak	13	3
Cancer concern	13	0
Information	15	2
Total (%)	164 (100%)	21 (12.8%)

A final version (VF) was produced in Brazilian Portuguese, which preserved equivalent concepts and was easy to understand for the target population. This version can be obtained for academic purposes free of charge¹¹.

DISCUSSION

The FACE-Q Head and Neck Cancer questionnaire was designed to assess satisfaction with specific functional, aesthetic and psychological aspects of head and neck cancer⁵⁻⁷. After translation, cultural adaptation and linguistic validation, the questionnaire must be applied in its original language or in other languages. So far, the questionnaire is only available in English.

Our process used the same methodology as other studies that translated the FACE-Q¹²⁻¹⁶, focusing on a translation that maintains the original semantics and idea of the questions, avoiding literal translation to facilitate patient understanding. Using official guidelines from the World Health Organization (WHO) and the International Society for Pharmacoeconomics and Outcome Research (ISPOR), we obtained a linguistically validated translation of the English module FACE-Q Head and Neck Cancer into a semantic, idiomatic and conceptually equivalent version. in Brazilian Portuguese^{10,17,18}.

Experienced translators in the health area proved essential, as they often use different terms than non-specialists¹⁷. Furthermore, the interview with the patients (Step 4) proved useful in our case, as the patient feedback was broad and led to critical linguistic changes.

Although the translation is primarily accurate concerning the original questionnaire, a literal translation is never possible, so there is always a slight interpretation bias.

CONCLUSION

After the process of translation, cultural adaptation and linguistic validation, the FACE-Q Head and Neck Cancer questionnaire in the Brazilian Portuguese version presents a version equivalent to the original instrument in English, which can be used as an acritical evaluation of patient-reported outcomes (PRO), both in research and in clinical practice.

COLLABORATIONS

- VPFP** Analysis and/or interpretation of data, Conception and design of the study, Writing - Preparation of the original
- RCL** Statistical Analysis, Data Collection, Conception and Design of the Study
- AMBB** Statistical Analysis, Data Collection, Conception and Design of the Study
- CPL** Statistical Analysis, Data Collection, Research
- RMCT** Methodology, Supervision, Validation
- FFB** Final Manuscript Approval, Project Management, Supervision
- RG** Final Manuscript Approval, Resource Management, Project Management

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