

ADAPTATION OF THE QUESTIONNAIRES “THE INTERSTITIAL CYSTITIS SYMPTOM INDEX AND PROBLEM INDEX” AND “PELVIC PAIN AND URGENCY/FREQUENCY (PUF) PATIENT SYMPTOM SCALE” TO THE BRAZILIAN CULTURE

Hypothesis / aims of study

The diagnosis of Painful Bladder Syndrome/Interstitial Cystitis (PBS/IC) is still a challenge due lack of universally accepted criteria, besides, the patient may present early, few symptoms, difficulting an accurate result. It can be given by examination of cystoscopy, urodynamic, potassium sensitivity testing, biopsy, laboratory tests and questionnaires. But none is conclusive, and it is believed that a symptom questionnaire to capture and record the presence of all (PBS/IC) symptoms is useful in helping to establish the diagnosis and that other resources can contribute to a more accurate diagnosis [1].

Since the questionnaires are an important aid for the diagnosis of PBS/IC, and in turn are not available in Portuguese in Brazil, it is necessary to translate and validate questionnaires developed, tested and used in other countries, to obtain an accurate diagnosis and, consequently, an appropriate treatment and better prognosis.

Therefore, the aim of this study is to adapt to the Brazilian culture the questionnaires "The Interstitial Cystitis Symptom Index and Problem Index" and "Pelvic Pain and Urgency/Frequency (PUF) Patient Symptom Scale".

Study design, materials and methods

The methodological process of cultural adaptation aims at the acquisition of an instrument true to the original, but adapted to the culture of the country where this version will be applied.

In this study the researchers opted for the directives developed by the American Academy of Orthopedic Surgeons, which has as a goal the standardization of the method for cultural adaptation of measuring instruments related to health, confirmed by theoretical findings and by the systematic review of published studies regarding the aforementioned methodology. Thus, the steps followed in this process were: translation of the original instrument by two different translators (T1 and T2); synthesis of the translations (T1 and T2); backward translation to the language of origin; assessment of the translation by a panel of specialists and pre-test [2].

In order to implement the present study the researchers got the formal authorization from the authors, so they could proceed to the translation and cultural adaptation of the instruments.

The instrument “The Interstitial Cystitis Symptom Index and Problem Index” is composed of two indices (symptom and problem) related to urinary symptom and pain symptom.

The instrument “Pelvic Pain and Urgency/Frequency (PUF) Patient Symptom scale” covers pelvic pain, including symptoms associated with sexual intercourse, as well as urinary urgency/frequency.

Results

Both instruments were analyzed by a specialist committee composed of an urologist, a methodologist, a linguist, a patient with a clinical diagnosis of interstitial cystitis and the researchers. The specialists produced individual considerations for each item in both instruments before of meeting, and the agreement rate in their opinions was calculated based on their answers. The committee meeting lasted about three hours and thirty minutes. With a percentage agreement of 100% among specialists, it was need to amend seven items, including questions and answer choices in the questionnaire "The Interstitial Cystitis Symptom Index and Problem Index". The expression "need to urinate with little or no warning" has been replaced by the word "suddenly", the words "less than once in five" was replaced by "a few times," the word "approximately" was replaced by the word "almost" and the word "often" was replaced by "many times". It was necessary to change six items, including title, layout, questions and answer alternatives of the instrument "Pelvic Pain Urgency / Frequency (PUF) Patient Symptom Scale." The expression "sexual act" was substituted for "sex intercourse" and the word "urgency" was replaced by "strong desire", also with a percentage of 100% agreement among experts.

A feature of the two questionnaires is that they are self-reported and thus the researchers realized that to achieve cultural equivalence, all of these items need to be changed, in order to make the instruments more easily understandable to the target audience.

Interpretation of results

The use of two translations (T1 and T2) allowed small corrections of referential and generic meaning, which in turn elicited an adequate synthesis of the translations.

The specialist committee meeting, although long, elicited the final understanding of the instruments. The connection that came from the healthcare and linguistics professionals was enriched and facilitated by the presence of the representant of the target population (woman with Interstitial Cystitis).

All the changed items indicate the need to adapt the questionnaires developed in other countries to Brazilian culture. In the next step we intend to perform a pre-test among Brazilian patients with interstitial cystitis, using the final questionnaires versions in Portuguese and, consecutively, to investigate the validity and reliability of both instruments.

As the instruments are very simple, we believe that they can be useful for healthcare professionals, in different scenarios of practice, promoting multidisciplinary actions.

Concluding message

The adaptation of the instruments "The Interstitial Cystitis Symptom Index and Problem Index" and "The Pelvic Pain Urgency/Frequency (PUF) Patient Symptom Scale" to the Brazilian culture was adequately accomplished. The use of a minutely defined methodology was able to produce a Portuguese version that is equivalent to the original in English.

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<i>Is this a clinical trial?</i>	No
<i>What were the subjects in the study?</i>	HUMAN
<i>Was this study approved by an ethics committee?</i>	Yes
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<i>Was the Declaration of Helsinki followed?</i>	Yes
<i>Was informed consent obtained from the patients?</i>	Yes