



Translation and cultural adaptation of the King's Brief Interstitial Lung Disease health status questionnaire for use in Brazil

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ABSTRACT

Objective: To translate the King's Brief Interstitial Lung Disease (K-BILD) questionnaire to Portuguese and culturally adapt it for use in Brazil. The K-BILD quantifies the health status of patients with ILD. **Methods:** The process involved the following steps: authorization from the author of the original (English-language) questionnaire; translation of the questionnaire to Portuguese by three translators, working independently; merging of the translations by a committee of specialists; back-translation of the questionnaire to English; revision and readjustment of the back-translation by the committee of specialists; evaluation by the original author; revision of the back-translation; cognitive debriefing (verification of the clarity and acceptability of the Portuguese-language version in the target population—i.e., patients with ILD); and finalization of the Portuguese-language version. **Results:** In the cognitive debriefing step, 20 patients with ILD were interviewed. After the interviews, the clarity and acceptability index of each question was ≥ 0.8 , which is considered acceptable. **Conclusions:** The Portuguese-language version of K-BILD appears to be easily administered to and understood by patients with ILD in Brazil. To our knowledge, this is the only instrument in Brazilian Portuguese that is designed to evaluate the impact that ILD has on the various aspects of the lives of those it affects.

Keywords: Lung diseases, interstitial; Pulmonary fibrosis; Surveys and questionnaires.

INTRODUCTION

Interstitial lung disease (ILD) is a term that refers to a group of chronic and progressive conditions characterized by inflammation and fibrosis of the lung parenchyma, directly associated with mortality.⁽¹⁾ According to a study from 1994, the incidence of ILD in New Mexico, USA, was 26-32 cases per 100,000 population per year.⁽²⁾ In Brazil, a survey conducted by the Department of Informatics of the Unified Health System showed that, in 2010 alone, the incidence of idiopathic pulmonary fibrosis was 4.84 cases per 1,000,000 population.⁽³⁾

As described in the literature, patients with ILD often present with dyspnea symptoms that limit their physical activity levels.⁽⁴⁾ The quality of life of those patients depends on various factors, such as the symptoms of the disease itself, the side effects of drug therapy, the natural progression of respiratory dysfunction, and morbidity-related functional limitations.⁽⁵⁾ ILDs are characterized by symptoms such as dyspnea, reduced lung volume, reduced gas exchange, reduced tolerance to exercise, diaphragmatic weakness, expiratory muscle fatigue after maximal exercise, and impaired peripheral muscle function. The condition also reduces patient quality of life and survival.⁽⁶⁻⁹⁾

ILDs are often diagnosed late,⁽¹⁰⁾ mainly because of the limited knowledge of health care professionals and the lack of local resources. Different ILDs have different prognoses and treatments, and it is difficult to establish accurate prognoses for patients with newly diagnosed ILD, because the natural history of the disease can vary.⁽¹¹⁻¹³⁾ The treatment of ILD aims to improve patient health in a broad sense. The impact of treatment can be measured by means of the support of specific questionnaires (disease-specific instruments), which are more responsive than generic instruments.⁽¹⁴⁾

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There is a shortage of specific instruments to measure the health status of patients with ILD. With the objective of developing a brief, easy-to-administer, validated tool, Patel et al.⁽⁴⁾ developed ILD-specific instruments. One of those is the King's Brief Interstitial Lung Disease (K-BILD) health status questionnaire, which was originally written in English but has already been translated into several languages and adapted for use in different countries. The lack of specific instruments and objectives for certain diseases affects their diagnoses, as well as the choice of therapies and interventions.^(15,16) The process of developing such instruments is thorough and time-consuming. Therefore, translating and culturally adapting a questionnaire that has already been validated in another language for use in different countries and cultures can be extremely valuable for the evaluation, follow-up, and diagnosis of the patients for whom it was developed.^(15,17)

In this context, the need for translating and culturally adapting this specific instrument (K-BILD), which measures the health status of patients with ILD, to Brazilian Portuguese is justified. The objective of the present study was to translate and culturally adapt the K-BILD questionnaire to Brazilian Portuguese.

METHODS

Our study focuses on the cultural adaptation and translation of a specific instrument (K-BILD) that measures the health status of patients with ILD for use in Brazil. The study was approved by the Human Research Ethics Committee of the *Universidade do Sul de Santa Catarina* (protocol no. 2.296.776/2017). The study is in accordance with the ethical precepts on research involving humans of the Brazilian National Health Council (Resolution 466/2012).

A process of translation and cultural adaptation should always evaluate the clarity, acceptability, comprehensibility, and reproducibility of the instrument in its target population. This is the step we denominate cognitive debriefing. To this end, all ILD patients who were undergoing treatment and having routine appointments at the Pulmonology Outpatient Clinic of the *Hospital Universitário Polydoro Ernani de São Thiago* of the *Universidade Federal de Santa Catarina*, located in the city of Florianópolis, Brazil) between October of 2017 and March of 2018 were invited to participate in the study.

The inclusion criteria were having a clinical diagnosis of ILD; being older than 18 years of age; being literate; and having given written informed consent for participation.

For the interview with the study participants, we used version 4 of the K-BILD questionnaire, already translated and adapted, to assess the comprehensibility and acceptability of each question. All the comments made by the participants were registered. The participants also completed a clinical survey covering the following topics: sociodemographic data, age, gender, ethnicity, marital status, level of education, ILD diagnosis,

comorbidities, the modified Medical Research Council Dyspnea Scale classification,⁽¹⁸⁾ and CT and spirometry findings for the diagnosis of ILD. Participation in the study did not incur in any expenses for participants, nor did it change the proposed treatment.

The methodology for translating and culturally adapting a questionnaire to a foreign language, different from the one in which the instrument was originally written, encompasses several steps. The steps of the protocol used in the present study were: 1) preparation: author's authorization for the study (rights to use, translate, and culturally adapt the instrument); 2) translation of the K-BILD from English to Brazilian Portuguese: three people performed a blind translation of the questionnaire (two native speakers of Portuguese with fluency in English and one native speaker of English with fluency in Portuguese); 3) merging: comparison and merging of the three Portuguese translations to create one single version in Portuguese, designated version 1; 4) back-translation: a literal back-translation of version 1 into English by a native speaker of English who was fluent in Portuguese and who was blinded to the original questionnaire. This version was designated version 2 (in English); 5) revision and readjustment of the back-translation: comparison of the back-translation with the original English version. Because the two English versions were very similar, no changes had to be made; 6) evaluation by the original author: version 2 was sent to the author of the K-BILD for analysis. The author made comments about items 3 and 6 of the questionnaire. Based on these observations, a new version was created: version 3 (in English); 7) revision of version 3: analysis of version 3 by the review committee and preparation of version 4 (in Portuguese); 8) cognitive debriefing: in this step we applied the questionnaire to 20 patients with ILD who agreed to participate in the study; the objective was to assess the clarity of the instrument as a whole so as to enhance it and improve its comprehensibility. All items were analyzed according to the instrument's Likert scale, and all comments made by the participants were registered; and 9) preparation of the final version: meeting of the review committee for the production of the final version of the instrument adapted for use in Brazil. Figure 1 illustrates the steps of the process.

RESULTS

During the study period, 95 patients with ILD were seen at the pulmonology outpatient clinic of the institution. Of those, 20 were included in the cognitive debriefing step of the study. The age of the participants ranged from 32 to 77 years, whereas the level of education ranged from complete primary education (50%), to complete secondary education (40%), and complete higher education (10%). The most common complaint was shortness of breath when exercising and performing activities of daily living—mentioned by 17 participants (85%), who had scores > 2 in the modified Medical Research Council scale.⁽¹⁸⁾ Table

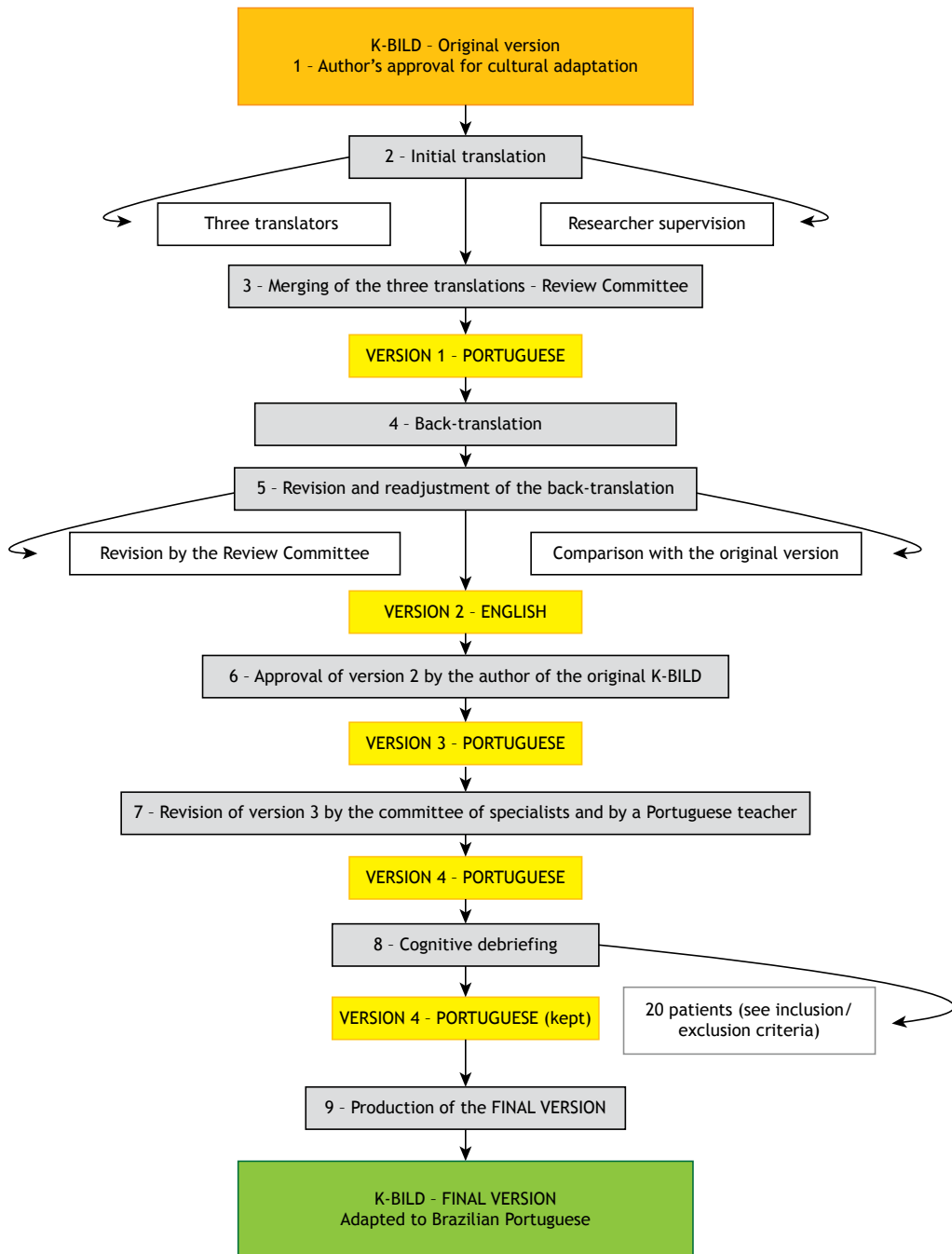


Figure 1. Summary of the process of translation and cross-cultural adaptation of the King’s Brief Interstitial Lung Disease (K-BILD) questionnaire to Brazilian Portuguese.

1 describes the clinical and functional status of the study participants.

The versions produced by the translators generated no doubts or corrections. A back-translation of the K-BILD was done and sent to the author for evaluation, who responded with the following remarks: 1) in item 3: the original term “severe” had been back-translated as “severity”. The committee gave the author a complete explanation of the concept in Portuguese and he decided that the term “*gravidade*” or “severity” be kept; 2)

in item 6, the author questioned the use of the word “tired” or “*cansado*” in Portuguese clarifying that the term should refer to a feeling of low self-esteem related to depression or, in his words, “feeling low in mood, like depression”. The committee, then, suggested replacing the term “*cansado*” or “tired” with “*incomodado*”, which means “annoyed”, “bothered”. The suggestion was well received by the author, who considered the semantics of the term equivalent to that of the original version. The committee of specialists’ revision conducted

Table 1. Characteristics of the participants in the study (N = 20).^a

Characteristic	Result
Age, years ^b	59 (32-77)
Gender	
Female	14
Male	6
Ethnicity	
White	16
Brown	3
Indigenous	1
Level of education	
Primary education	10
Secondary education	8
Higher education	2
Diagnosis of ILD	
Interstitial lung disease secondary to collagen disease	3
Idiopathic pulmonary fibrosis	5
Nonspecific interstitial pneumonia	6
Chronic hypersensitivity pneumonitis	3
Alveolar proteinosis	2
Sarcoidosis	1
mMRC scale score	
0	3
2	9
3	5
4	3
Associated morbidities	
Systemic arterial hypertension	12
Dyslipidemia	6
Chronic kidney disease	2
Gastroesophageal reflux disease	1
Diabetes mellitus	1
Pulmonary function ^c	
FEV ₁ , % of predicted	65.5 (56.2-76.7)
FVC,% of predicted	66.5 (57.7-83.7)
FEV ₁ /FVC % of predicted	98.5 (92.5-108.5)

ILD: interstitial lung disease; and mMRC: modified Medical Research Council scale. ^aValues expressed in n, except where otherwise indicated. ^bValues expressed in median (minimum-maximum). ^cValues in median [interquartile range]. Reference values according to Crapo et al.⁽¹⁹⁾ Patients evaluated while using their control medication, prior to the use of bronchodilators.

after this step showed no grammatical errors; the formatting of the questionnaire with a horizontal Likert scale was kept.

In the cognitive debriefing step, we asked about the participants' understanding of each statement and how appropriate they thought it was. We gave a clarity score between 1 and 10 for each item based on participants' understanding of the wording of that statement. On that occasion, we defined that scores between 1 and 4 would indicate a confusing statement that should be rewritten; scores between 5 and 7 would indicate an unclear statement that should be clarified; and scores between 8 and 10 would indicate a clear statement. To assess the clarity, acceptability, and comprehensibility of the instrument, each participant was asked to comment on each item with a score below

8.^(20,21) Questions with a clarity index above 80% were accepted without further corrections.

The clarity index was defined by calculating the mean of the sum of the item scores given by the participants. The clarity index of each question was: 1) 9.50; 2) 9.15; 3) 9.50; 4) 9.60; 5) 9.05; 6) 9.15; 7) 8.80; 8) 9.30; 9) 9.65; 10) 9.40; 11) 9.45; 12) 9.20; 13) 9.30; 14) 9.25; and 15) 9.45. All means were above 8.0; therefore, we did not need to modify any of the terms, and version 4 in Portuguese was kept as the final version.

All data were registered in a separate record (available to those involved in the study) and will be kept for 15 years. All the study data will be filed in the archives of the pulmonology outpatient clinic of the institution and kept confidential, in accordance with the national and international good clinical research practice guidelines.

DISCUSSION

In the present study we described the process of translating the K-BILD—an instrument for the assessment of the health status and quality of life of patients with ILD⁽⁴⁾—to Brazilian Portuguese and its cultural adaptation for use in Brazil. The Portuguese version of the K-BILD that we developed (Supplement S1) is technically and semantically equivalent to the original version.⁽⁴⁾ The challenges of culturally adapting an instrument are manifold, and, given Brazil's huge territory, there are many regional and sociocultural differences to be taken into consideration, in addition to the problem of the significant illiteracy rates in certain regions, which makes it even more difficult to adapt instruments like this and make sure they are comprehensible and relevant in the entire country. During the process of cultural adaptation, the committee of specialists analyzed the different domains addressed by the original instrument in terms of their relevance and appropriateness to the new cultural context and concluded they were all pertinent.⁽²²⁾ In this process, words of common usage in oral register were chosen, aiming to facilitate the understanding of the questions. It is widely known that the level of education as well as reading and interpreting skills are very important variables in this type of population studies, which they may affect the results.⁽¹⁵⁾ Therefore, simple vocabulary words and shorter sentences were used to facilitate the reading by people with limited vocabulary and lower levels of education. Region-specific terms commonly found in oral and written Brazilian Portuguese were avoided.

After translating and back-translating the original instrument, we asked the target population about

their understanding of the concepts addressed by the questionnaire. Their inputs enabled the committee of specialists to have a more comprehensive approach to their considerations and gave them more confidence in the semantic equivalence of the final version, decreasing the likelihood of it including inappropriate or ambiguous terms and, thus, creating a version that would be a good fit to the socioeconomic background of the target population. This process enabled us to achieve semantic (actual meaning of words) and idiomatic (interpretation of colloquialisms) equivalence. By adopting a strict methodology to reduce regionalism and, at the same time, making the most of this myriad of aspects that make up the Brazilian culture, the present study contributes to the efforts to provide the scientific community with a useful tool for assessing the health status of patients with ILD.

We expect that, with the validation of the K-BILD questionnaire in Portuguese, it can be used as a reference by multidisciplinary teams in Brazil providing ILD patients with follow-up and treatment, and contribute to the improvement of their quality of life. This questionnaire will also enable further studies on ILD, as it is an appropriate and effective instrument for assessing the health status of patients with this condition.

In conclusion, the K-BILD questionnaire has been successfully translated to Brazilian Portuguese and culturally adapted for use in Brazil. To our knowledge, it is the only instrument available in Portuguese to assess the impact of ILD on different aspects of life in patients with the disease.

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