Objective: Develop the translation and cultural adaptation of the Questionnaire for Identifying Children With Chronic Conditions-Revised (QuICCC-R), published in 1999 for Brazilian Portuguese. The questionnaire was developed to identify children with chronic conditions through the application, to their parents or responsible caregivers, of 16 questions about the repercussions of these conditions, such as functional limitations, dependence on compensatory mechanisms or care and higher-than-expected service use for their age. The method used does not depend on diagnoses. The questionnaire can be applied face to face or by telephone and takes two minutes on average.

Methods: Methodological study, developed in the following stages: translation, back-translation, expert review 1, pretest, expert review 2 and calculation of content validity index.

Results: The questionnaire was translated and adapted to Portuguese, guaranteeing the semantic, idiomatic and cultural equivalence. The pretest and content validation by the expert committee (index 0.99) permitted the improvement of the questionnaire for the sake of application and understanding by the target audience.

Conclusion: Being fast and easy to apply, the questionnaire can contribute to identify the chronic childhood condition in clinical practice and in epidemiological studies, supporting planning in health.

Abstract

Objective: Realizar a tradução e adaptar cultural do Questionário para Identificação de Crianças com Condições Crônicas (QuICCC-R), publicado em 1999 para a língua portuguesa do Brasil. O questionário foi desenvolvido para identificar crianças com condições crônicas por meio da aplicação, aos seus pais ou responsável, de 16 questões sobre as repercussões dessas condições, como limitações funcionais, dependência de mecanismos compensatórios ou de cuidados e utilização de serviços acima do esperado para a idade. O método utilizado é independente de diagnósticos. A aplicação do questionário pode ser feita pessoalmente ou por telefone, com duração média de 2 minutos.

Métodos: Estudo metodológico realizado nas seguintes etapas: tradução, tradução reversa, revisão por especialistas 1, pré-teste, revisão por especialistas 2 e cálculo do índice de validade de conteúdo.

Resultados: O questionário foi traduzido e adaptado para português garantindo a equivalência semântica, idiomatica e cultural. O pré-teste e a validação de conteúdo por comitê (índice 0.99) possibilitaram aperfeiçoar o instrumento para aplicação e compreensão pela população alvo.

Conclusão: Por ser um instrumento de rápida e fácil aplicação, o questionário pode contribuir para identificação da condição crônica na infância, na prática clínica e em estudos epidemiológicos, subsidiando o planejamento em saúde.

Resumen

Objetivo: Traducir y adaptar al portugués brasileño el Questionnaire for Identifying Children With Chronic Conditions-Revised (QuICCC-R), publicado en 1999. Fue desarrollado para identificar niños con condiciones crónicas mediante aplicación a padres o responsables de 16 preguntas sobre las repercusiones de tales condiciones, como limitaciones funcionales, dependencia de mecanismos compensatorios o de cuidados y utilización de servicios superior a la esperable para la edad. El método utilizado es independiente de los diagnósticos. El cuestionario puede completarse personal o telefónicamente, en tiempo promedio de 2 minutos.

Métodos: Estudio metodológico realizado en etapas: traducción, retrotraducción, 1ra. revisión por especialistas, prueba piloto, 2da. revisión por especialistas y cálculo del índice de validez de contenido.

Resultados: El cuestionario fue traducido y adaptado al portugués, garantizándose la equivalencia semántica, idiomática y cultural. La prueba piloto y la validación de contenido por comité (índice 0.99) permitieron perfeccionarla para su aplicación y comprensión por parte del público objetivo.

Conclusión: Constituye un instrumento de rápida y fácil aplicación, el cuestionario contribuye a la identificación de condiciones crónicas en la infancia y la práctica clínica y en estudios epidemiológicos, colaborando con la planificación en salud.
Introduction

Chronic conditions in childhood have increased worldwide in the last decades and now represent a considerable part of childhood morbidity. In the Brazilian literature, multiple definitions of chronicity in childhood exist. Nevertheless, the criteria and instruments to identify and characterize these children is incipient. In this context, the choice and incorporation of a concept of chronic condition that can be operated through instruments for use in clinical practice and in research is relevant for the planning of health care and the elaboration of public policies.

For this study, we chose the definition of chronic childhood conditions developed based on the studies carried out by Research Consortium on Children With Chronic Conditions, which includes biological, psychological or cognitive conditions that have lasted or have the potential to last at least one year and produce one or more of the following repercussions: limitations of function, activity or social role compared to children of the same age without changes in growth and development; dependence, to compensate or minimize the functional limitations, medication, special diet, technological devices or care; higher-than-usual need for health care or related services, psychological services or educational services for the child’s age, in relation to treatments, interventions or special accommodations.

This same definition guided the development of methods to identify children with chronic conditions, such as the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) and Questionnaire for Identifying Children with Chronic Conditions-Revised. For this purpose, criteria were used that are based on the repercussions of the chronic conditions, such as functional limitations, dependence on compensatory mechanisms or care and higher-than-expected use of services for the age.

The QuICCC-R (1999), which is the focus of this study, is a reduced version of the QuICCC, with 87% sensitivity, 90% specificity, positive predictive value of 93%, negative predictive value of 82% and K of 0.78. It is considered a satisfactory alternative for population surveys and has been used internationally in follow-up studies of premature and low birth weight infants. In the United States and Sweden, the questionnaire was used to verify the rate of chronic conditions in follow-up studies of newborn cohorts, respectively, weighing less than 1000 g and with gestational age less than 26 weeks. In these cohorts, there were higher rates of chronic conditions between 8 and 14 years when compared to children in the control group. Among the children with chronic conditions, the following were found: developmental delay, drug dependence, enteral diet, glasses, hearing aid, walker and wheelchair, need for help to walk, eat, dress, take a bath and go to the bathroom, besides the higher-than-expected need to use services for the age. The results of the questionnaire show the specific health and education needs of these children in the long term, which should be taken into account in the planning of services in these sectors.

On average, the application of the questionnaire takes two minutes, in person or by telephone. It consists of 16 questions that address the repercussions of having a chronic health condition, relate them as a result of a health condition and refer to the criterion of duration of this condition for a year or more. For the condition of a child to be considered chronic, the answers need to be affirmative to all parts of at least one question in the questionnaire. The QuICCC-R (1999) should be applied to the child’s parents or responsible caregivers, who should be knowledgeable about their health and their daily lives.

Recognizing the insufficiency of epidemiological data related to children with chronic conditions and their identification in the country’s health services, the use of these instruments in Brazil can contribute to know and give visibility to these children. It also permits reflections on the care provided to this group and reorganization of the care model, considering health as well as education and social services, favoring the continuity of care and attendance to their specific needs.

Thus, this study aims to perform the translation and cultural adaptation of the Questionnaire...
Questionnaire for identifying children with chronic conditions (QuICCC-R): translation and adaptation

for Identifying Children with Chronic Conditions - Revised to Brazilian Portuguese.

Methods

A methodological translation and cultural adaptation study of the QUICCC-R (1999) was carried out, which was developed in 2012. Therefore, the framework proposed by Beaton, Bombardier and Guillemin was used. In accordance with the proposal, the following stages were undertaken: translation to Brazilian Portuguese, synthesis, back-translation to English, review by expert committee 1, pretest 1, pretest 2, review by expert committee 2 and calculation of Content Validity Index (CVI).

For the translation, cultural adaptation to Brazilian Portuguese and use of the QuICCC-R (1999), authorization was obtained from the responsible authors, affiliated with the Department of Pediatrics of the Albert Einstein College of Medicine in New York, who developed the questionnaire in 1999 in partnership with the Maternal and Child Health Bureau (MCHB) (Figure 1).

Translation, cultural adaptation and content validation process of the QuICCC-R

Stage I – Initial translation

Two bilingual native Portuguese translators translated the QUICCC-R (1999) questions into Brazilian Portuguese. One of them (Translator 1) had an educational background in health and was knowledgeable on the concepts covered in the questionnaire (undergraduate degree in physiotherapy, doctorate in health sciences with emphasis on the health of children and adolescents and doctoral training in Canada, active in teaching); the other (Translator 2) had no educational background in health training and was not knowledgeable on the concepts covered (undergraduate degree in psychology, English proficiency certification by the University of Michigan, acting as a translator).

Figure 1. Translation, cultural adaptation and content validation process of the QuICCC-R (1999)
versions of the instrument (T1 and T2), the translators elaborated a report containing the doubts and options made in the translation.

**Stage II - Translation synthesis**
The two translations to Brazilian Portuguese (T1 and T2) were compared in cooperation among Translators 1 and 2 and a researcher, and a consensus was established on the differences found in the translations and Portuguese Version 1 was prepared.

**Stage III - Back-translation**
Two translators independently translated version 1 in Portuguese into English (Translators 3 and 4). These translators were native English speakers and had no educational background in health. The translators prepared a report with the doubts and options made in the translation. As the purpose of this step is to compare the back-translations (TR1 and TR2) with the original version, the translators of this step did not have access to the questionnaire.

**Stage IV - Expert committee review 1**
The Committee consisted of four participants, including two authors, who have a health background and work in child health (undergraduate degree in nursing, master’s and doctorate in nursing with emphasis on child health, acting in research, teaching and care), and by two translators involved in the process (Translators 1 and 2). The translations (T1, T2, TR1, TR2) were revised, considering the original questionnaire and the reports prepared by the translators. Based on the revision, Version 2 was developed in Portuguese.

In order to guarantee the cultural adaptation of the instrument, the semantic (evaluation of words observing grammatical and vocabulary aspects), idiomatic (related to colloquialisms that cannot be translated literally) and cultural (observation if the presented situation is part of the daily life experience in the cultural context of the society) equivalence of each question was evaluated. (16)

**Stage V - Pretest 1**
The pre-test permits verifying how the questionnaire is interpreted at the time of application and the need for changes. (16) Considering that the instrument was constructed to be applied face-to-face or by telephone, the pretest was executed using these two forms of application. Initially, version 2 in Portuguese of the questionnaire was applied personally by the researchers involving 19 responsible caregivers of children between 18 days and 12 years of age, who were hospitalized in the pediatric unit of a public hospital. During the pretest, the researchers used a version of the questionnaire to which a blank space was added after the answers to each question, which served to record their application difficulties and to manifest doubts. The records during the application of the questionnaire were used to prepare Version 3 in Portuguese.

**Stage VI – Pretest 2**
Version 3 was used for face-to-face application to the responsible caregivers of 65 children, aged up to 12 years, distributed in all age groups, who were hospitalized in the pediatric unit of a public hospital; and by telephone to the responsible caregivers of 44 children, aged between 1 year and 2 years and 4 months old, who had been discharged from neonatal units. In both applications, no doubts were verified, so that it was not necessary to elaborate another version of the questionnaire. It is recommended that the pretest be performed with 30 to 40 participants. (16)

**Stage VII - Expert committee review**
Expert Committee 2 evaluated Version 3 in Portuguese. Then, the interrater agreement on the parts of the questionnaire was verified by calculating the Content Validity Index (CVI). (17) The Committee consisted of 14 professionals, including nurses, physiotherapists, speech therapists, physicians and occupational therapists, whose educational background included emphasis on child health and who worked in child care or researched in the area. The professionals individually scored each question on a Likert scale, ranging from 1 to 4 (1 not clear, 2 hardly clear, 3 quite clear and 4 very clear), according to their understanding.

To calculate the CVI of each question, the sum of the number of parts the evaluators that received
scores 3 or 4 was calculated and divided by the total number of answers to each question. The parts of the questions that received scores 1 or 2 were reviewed, considering the suggestions the evaluators had registered. To evaluate the questionnaire as a whole, the mean of the CVIs assigned to each of the 16 questions and the three instructions of the questionnaire were calculated. Content Validity Indices equal to or higher than 0.8 were considered as acceptable interrater agreement coefficients.\(^{(17)}\)

All stages of the study were carried out in accordance with Resolution 466/2012 of the National Health Council for research involving human subjects. The project received approval from the Ethics Committee (opinion 0004.0.439.203-10) and the participants in the pre-test were informed about the study and signed the Free and Informed Consent Form.

## Results

### Evaluation of semantic, idiomatic and cultural equivalence

Chart 1 displays the synthesis of translations into Brazilian Portuguese. The translations (T1 and T2) were generally similar and the words and expressions used in the unified version (Version 1 in Portuguese) were chosen to facilitate the responsible caregivers’ understanding of the questions, searching for semantic, idiomatic and cultural equivalence of the instrument. Among the divergent or non-comprehensible terms in translations 1 and 2, which the researcher discussed with the translators, counselor, tutoring and resource room stood out.

In chart 2, the synthesis of the back-translations of Version 1 in Portuguese (TR1 and TR2) and of Version 2 in Portuguese, defined by Expert Committee 1. Despite the similarity between the back-translations and the original version, some words and expressions were modified because they were considered unsatisfactory for the target audience's understanding of the questionnaire. An example is question 1b, in which “já dura” was replaced by “vem acontecendo” and “esperado que dure” was replaced by “esperado que continue acontecendo”.

### Evaluation of the pretest

During the face-to-face application of Version 2 in Portuguese of the questionnaire, in general, the children’s responsible caregivers were able to answer the questions, demonstrating understanding of what was being asked. Doubts were presented when answering two questions (2 and 3), and the author of the QuICCC-R (1999) was contacted for clarification.
In question two, “(Name) presents allergic reactions that endanger your life?”, doubts arose about what was life threatening. In contact with the authors, it was evidenced that the risk would be related to allergic reactions that could progress to anaphylaxis. In question three, “Did some doctor tell you that (Name) needs to follow a special diet or avoid certain foods?”, the participants were in doubt as to what a “special diet” would be. It was important for the applier of the questionnaire to indicate that it could relate to the type of food, the consistency or the route of administration. Therefore, these clarifications for the application were incorporated in the manual of Portuguese Version 3.

In the face-to-face and telephone application of Portuguese Version 3, the children’s caregivers were able to understand and answer the questions in the questionnaire based on the clarifications.

### Content Validation

In Expert Committee 2’s first evaluation of Version 3 of the questionnaire, it was observed that three questions (Q9, Q10 and Q16) and two instructions (I2 and I3) had a mean CVI of 1; four questions (Q12, Q13, Q14 and Q15) and one instruction (I1) had a mean CVI superior to 0.8; and nine questions (Q1, Q2, Q3, Q4, Q5, Q6, Q7, Q8 and Q11) had a CVI between 0.6 and 0.8. Evaluating the questionnaire as a whole showed a mean CVI equal to 0.8, sufficient for the content validation.(17)

Considering the possibility of improving the CVI of each of the questions, the researchers decided to make the modifications the experts had suggested and then re-evaluate the instrument. In the second evaluation by Expert Committee 2, the average CVI of 12 questions was equal to 1 and of four questions superior to 0.9, which indicates high interrater agreement on the clarity and representativeness of the translated instrument. The mean CVI of the instrument as a whole was 0.99, considered appropriate for content validation.(17) This resulted in the final Brazilian Portuguese version of QuICCC-R (1999) (Figure 2).
Discussion

The translation and cross-cultural adaptation of previously developed instruments are fundamental for the Target population to understand these tools in another cultural context, as well as to permit comparing epidemiological research results undertaken in different places.\(^{(18)}\) International studies that used the QuICCC and QuICCC-R (1999) granted visibility to the increase in chronic childhood conditions and the care needs of this group of children, supporting the planning of health and education services.\(^{(3-6)}\)

High methodological rigor is required in the adaptation process to compare the results obtained based on different versions of an instrument for different locations and cultures.\(^{(17)}\) What is perceived is that many are not properly validated.\(^{(19,20)}\) The strategies and procedures adopted approach recommendations proposed based on a review of the literature on the subject and the method adopted in other translation and cultural adaptation studies.\(^{(21,22,24)}\)
In the translation and adaptation process of this study, most of the different words and expressions presented equivalent or similar meanings. Some words and expressions needed to be adapted and a term had to be omitted to facilitate the understanding of the target population of the study, words and expressions needed to be replaced by synonyms, pronouns and verb tenses had to be standardized, aiming to guarantee the pertinence and acceptability of the style used. The need for these adaptations was mentioned in other studies, the adaptation process being described as “a combination of literal translation of words and phrases from one language to another and an adaptation that contemplates the cultural context and lifestyle of the target population.” (18,19,25)

In question five, we chose to omit the word counselor, a term that refers to the counselor who can act in school, health or legal services, and who can be a psychologist, pedagogue, psycho-pedagogue, physician, lawyer, social worker, among others. In Brazil, in the case of the health area, psychologists and social workers are professionals who, in most cases, take on the role of counseling. As the terms psychologist and social worker had already been mentioned in the question, the term counselor was omitted in the Brazilian version.

In question 14, “tutoring by a teacher or other professional, or resource room?”, the expression “resource room” refers to a room located within a regular school where students who have some type of learning difficulty receive individualized technical follow-up. In Brazil, specialized educational services are regulated by Decree 7,611 of November 2011, which led to the establishment of multifunctional resource rooms, especially in public education systems and religious or philanthropic community institutions. Thus, in the final version of the questionnaire, it was decided to replace the initially proposed “room for individualized school help” by the expression “room for specialized educational services”, with a view to coherence with the Brazilian legislation and context and the parents or responsible caregivers’ understanding, besides adopting words and expressions used in the inclusion discourse.

The observations registered regarding the comprehension difficulties during the pretest and the suggestions by the members of the Expert Committee 1 and 2 permitted enhancing the target population and the appliers’ (researchers or professionals) understanding of the instrument. (16,17) The fact that expert committee 1 did not include a linguistics professional is considered a limitation of the study, as this could contribute to clarify the possible uses of words and expressions and the limits of the English language in relation to its adaptability and correspondence to Portuguese. To mitigate the possible impacts of this limitation, the author of the instrument was contacted to clarify the use of the words and expressions according to the theoretical and practical assumptions adopted.

For the content validation, the evaluation by Expert Committee 2 was repeated to obtain a better mean CVI, considering the adopted reference value sufficient for the content validation (0.8 or higher). (17) In addition, the composition of the expert committee was defined to cover an appropriate number of professional from the different categories serving on the health team. Both professionals with clinical experience and professionals engaged in research in the area were included. (14)

**Conclusion**

The stages of the translation process were executed, in view of the necessary methodological rigor, and permitted guaranteeing the semantic, idiomatic and cultural equivalence. The translated version was adapted to make it understandable in the Brazilian cultural context, but aiming for maximum equivalence between the original and the translated version, in order to avoid distortions and permit comparisons between the results obtained from its application in different contexts. In conclusion, the translated and culturally adapted version of the QuICC-R (1999) in Brazilian Portuguese was successfully elaborated. The next step is to verify the psychometric properties of the instrument. As children with chronic conditions represent a clinical and socially vulnerable group, which is grow-
ing in Brazil, the importance of translating the QuICCC-R (1999) is highlighted, being an instrument that allows professionals and researchers to identify chronic childhood conditions in a speedy and simple manner. The use of the instrument can permit the mapping of the chronic childhood condition, supporting health practices, planning and policy-making in the country.

Collaborations

Duarte ED, Tavares TS, Nishimoto CLJ, Azevedo VMGO, Noelly e Silva BC and Silva JB declare that they contributed to the project design, data analysis and interpretation, relevant critical review of the intellectual content and approval of the final version for publication.

References

Erratum

In the article published in Acta Paul Enferm. 2018; 31(2):144-52, Duarte ED, Tavares TS, Nishimoto CL, Azevedo VM, Noelly e Silva BC, Silva JB; “Questionnaire for identifying children with chronic conditions (QuICCC-R): translation and adaptation”, the authors requested to publish the following errata: The author Vivian Mara Gonçalves De Oliveira Azevedo has institutional affiliation at Universidade Federal de Uberlândia, Uberlândia, MG, Brazil.