Translation and adaptation of “Perception of Severity of Chronic Illness” to the Brazilian culture for adolescents

Isabel de Moraes Lopes*, Priscila Peruzzo Apolinario* Maria Helena de Melo Lima*

ABSTRACT
Objective: To translate, adapt, and evaluate the applicability of the “Perception of Severity of Chronic Illness” questionnaire to the Brazilian culture for diabetic adolescents.

Methods: This is a methodological study consisting of the stages of translation, synthesis of translations, back translation, review by an expert committee, and pre-test. The expert judges evaluated semantic, idiomatic, conceptual, and cultural equivalences. The judges’ concordance was quantified using the Content Validity Index.

Results: The translation and back translation were performed successfully. After the synthesised translation was reviewed by the committee, the items were altered to ensure equivalence between the original and translated instrument. After the pre-test, some statements were reformulated to make them clearer and easier to understand. The preliminary data of the instrument’s reliability calculated using Cronbach’s alpha was 0.66.

Conclusion: The Brazilian version of the instrument Perception of Severity of Chronic Illness proved satisfactory in terms of the translation, cultural adaptation, and practicality, and it was considered an easily applicable and viable tool for clinical practice.

Keywords: Chronic disease. Diabetes mellitus. Validation studies. Translating. Adolescent.
INTRODUCTION

Diabetes mellitus (DM) is one of today’s most significant public health issues, and the fourth cause of death worldwide with a higher incidence in developing countries (4). Diabetes Mellitus (DM) is a chronic disease that, in the long term, reduces the quality of life, the ability to work and the life expectancy of sufferers, resulting in significant physical and psychological impacts for patients (5) and high costs for the public healthcare system (6). This complex condition calls for the management, monitoring, and appropriate measurement of patients adherence to drug and non-drug therapy (6).

The difficulty of patients in adhering to DM treatment is a worldwide problem that is recognised as being the main obstacle in the prevention of acute and chronic complications. Research has shown that adherence to treatment prescribed in the clinical practice, which includes diet and exercise recommendations, monitoring blood glucose, and glycaemic control, can be improved by changing patient perception of the disease and treatment of DM (5).

The patients’ self-perceptions of DM are beliefs regarding the cause, nature, and maintenance of disease, and may influence the choices of healthcare and proposed treatments, as well as the relationship that patients have with themselves and with the people they live with (6). In this respect, adolescents, children, and adults have different beliefs and perceptions, and manage their health problems in particular ways.

Adolescence involves a transition between childhood and adulthood with all the related biological and psychosocial changes, which can be challenging for adolescents with diabetes, their families, and the healthcare team. This stage among individuals with DM is often associated with the deterioration of metabolic control due to physiological and psychosocial factors, generating countless damage to diabetic adolescents (7).

Consequently, measuring and understanding the perceptions of adolescent diabetic patients of the disease can help predict health behaviours and identify critical factors of adaptation to the disease, as well as support interventions to modify or consider the specific cognition of these patients to achieve better health outcomes (5, 8). The instrument Perception of Severity of Chronic Illness (PSCI) (9) was created to assess the perception of the severity of chronic disease in adolescents with diabetes or cystic fibrosis. The PSCI was developed with the help of experts (psychiatrists, psychologists, and specialists) in behavioural science (9). This simple and short questionnaire with Likert-type answers is used in clinical practices to assess objective and psychosocial aspects related to chronic disease.

In the Brazilian culture, literature reveals a significant gap in relation to the use of instruments to assess how adolescent diabetic patients perceive the severity of this chronic disease. Given the importance of objectively assessing the perception of DM in Brazilian diabetic adolescents, and the recommendations found in literature to culturally adapt the instrument that are not available and validated in the desired content (10), the aim of this paper was to translate, adapt, and assess the applicability of the instrument Perception of Severity of Chronic Illness – PSCI (9) to the Brazilian culture for diabetic adolescents.

METHODS

This is a methodological study based on the investigation of methods to obtain, organise, and analyse data with the aim of building and validating research instruments and techniques (11). The purpose of the questionnaire adapted for use in Brazil was to assess the gravity of the perception of adolescents’ in relation to their health, and, consequently, to chronic disease (8).

The instrument consists of 14 statements that cover: (i) the perception of body image (items 1, 2, and 4); (ii) the perceived severity of the disease, including evolution of the disease and life expectancy (items 3, 8, and 9); (iii) the effects of chronic disease on physical activity and social life (items 5, 6, and 13); (iv) academic achievement, vocation, and future planning (items 7, 10, and 12); (v) reproductive potential (item 11); and (vi) relationship with parents (item 14) (9).

The 14 questions were based on an extensive literature review and consultations with experts. It is a brief instrument with statements in a Likert-type scale, designed to be self-responded with scores from 1 to 5 points, ranging from “strongly disagree” to “totally agree”. Score 1 denotes the lowest perceived severity of the illness, while score 5 refers to the highest perceived severity, with a maximum score of 70. There is a balance between the negative and positive statements, and the vocabulary used in the instrument is easy to understand (8).

The cultural adaptation was based on widely used recommendations in international literature (10). It consists of the following steps: authorisation of the principal author of the PSCI; Portuguese translation; synthesis of the translations; back translation; review by a committee of judges; and pre-test of the final version.
After obtaining the authorisation of the author of the instrument to adapt the PSCI, we initiated the translation to Brazilian Portuguese to accurately convey the context of the original to the Brazilian reality. According to the methodological recommendations\(^{(10)}\), we selected two independent translators who are fluent in English and are native speakers of Brazilian Portuguese.

One of the translators was informed of the purpose of the study to ensure cultural and idiomatic equivalence, resulting in the first translation (T1). The other translator translated the instrument without this knowledge (T2) to ensure the extraction of unexpected meaning from the original instrument. The researchers involved in the project compared the versions translated into Portuguese (T1 and T2) and subsequently prepared a consensual version in Brazilian Portuguese, named T1, 2.

Then, the back translation was initiated, which consisted in translating the consensual version (T1, 2) back to the source language (English). This procedure was used to verify whether the Portuguese version adequately corresponds to the English version, guaranteeing the quality of the cultural adaptation of the instrument. The back translation was completed by two independent translators who are native speakers of English. They had no knowledge of the objectives, the subject matter, or the original instrument. Each translator produced an English version (RT1 and RT2).

Subsequently, a committee of experts was formed to check the validity of the content of the synthesis version of the PSCI items, and to obtain the version for the pre-test\(^{(12)}\). The five judges who participated in this committee were a linguistics professor, a professor of nursing and specialist in diabetes, a professor of nursing, and a master of nursing, both of which have experience in the cross-cultural adaptation of scales; the authors of this study participated as methodologists.

The items of the instrument were assessed to obtain the semantic, idiomatic, cultural, and conceptual equivalences. The semantic equivalence refers to the meaning of words (vocabulary, grammar); the idiomatic equivalence refers to idioms and colloquialisms; the experimental equivalence covers situations that are consistent with the cultural context; and the conceptual equivalence refers to the explored concept\(^{(22)}\).

The original version, the translated versions (T1 and T2), the synthesis of the Portuguese translations (T1, 2), and the back translations (RT1 and RT2) were used to support the assessment of the instrument items. The purpose of this process is to ensure that the final translation preserves the meanings of the original English version, that the situations specified in the items actually evaluate the perception of the severity of chronic disease in adolescents, and to analyse whether the items are culturally relevant to the target population of this study\(^{(10)}\).

The evaluation of the committee of judges served to identify cultural issues and suggest changes and substitutions to make the instrument easier to understand. A second committee was composed of two methodologists and the person responsible for the translation synthesis to adapt the instrument and ensure conformity between the suggestions and the original instrument.

The Content Validity Index (CVI) was used to verify the concordance ratio between the judges who took part in this step. This index is used to analyse each item individually and, subsequently, the instrument as a whole. The correlation between the evaluators for each item of the instrument was measured using a Likert-type scale with scores from one to four (1 = not equivalent; 2 = impossible to assess equivalence without reviewing the item; 3 = equivalent, but requires minor changes, and 4 = absolutely equivalent). The items that scored “1” or “2” were reviewed or eliminated\(^{(12)}\). The CVI for each item was calculated by dividing the number of responses “3” or “4” by the total number of responses\(^{(12-13)}\). Literature recommends that for a committee of five judges, all the judges must agree for the decision to be representative\(^{(13)}\).

After validating the content, the pre-test was conducted with the adapted version of the PSCI on a sample of 30 adolescents (10 to 19 years)\(^{(14)}\) with DM type 1 or 2. The participants were informed of the purpose of the scale and its evaluation to ensure they understood the items and words, and clarified any queries as they completed the instrument. The study was conducted at a diabetes mellitus outpatient unit in a teaching hospital in the state of São Paulo, Brazil. All the subjects who were under the age of 18 and not accompanied by a responsible adult were excluded. The pre-test was conducted according to the service routine, between February and March 2015, before the nursing or medical appointments. Sociodemographic and clinical data were also obtained to characterise the patients.

The applicability of the Brazilian version of the PSCI has been investigated using a previously prepared and validated questionnaire\(^{(15)}\) to determine whether the statements of the instrument that was being adapted were easy to interpret, answer, and understand. This questionnaire was answered by the participants at the end of the pre-test, which helped to detect any problems they
had interpreting each statement and detect terms that were difficult to understand.

The pre-test data were subjected to descriptive analysis using the Statistical Package for Social Sciences (SPSS). The internal consistency of the instrument was analysed using Cronbach’s alpha (16). This coefficient ranges from 0 to 1, where values greater than 0.7 indicate reliability among the measurements (16). The analyses were completed using SPSS software, version 9.4. This study observed Resolution #466/12 of the national health council (17), and was approved by the research ethics committee of the local university (CAAE: 30803814.2.0000.5404/ Opinion: 729.509) on 13 July 2014. All the diabetic adolescents who agreed to participate in the study and their guardians signed two copies of an informed consent statement.

This article was extracted from the final course work “Tradução e adaptação transcultural do instrumento ‘Perception of Severity of Chronic Illness’, presented to the Faculdade de Enfermagem da Universidade Estadual de Campinas, Campinas, SP, Brazil (18).

RESULTS

The steps of translation, synthesis, and back translation were carried out satisfactorily. Subsequently, the semantic, idiomatic, conceptual, and cultural equivalences of each item of the PSCI were evaluated by the committee of judges. In this step, the CVI was calculated for each item in the synthesis version of the scale. Table 1 shows the agreement ratio of the experts.

In this evaluation stage, the items “Title”, “Likert scale 2”, “Likert scale 4”, and “Statement 1” obtained 100% concordance in all the equivalences and were kept unchanged. The CVI of the items “Introduction 2”, “Likert scale 1”, “Likert scale 3”, and “Likert scale 5”, and statements 2, 3, 5, 7, 8, 9, 10, 11, 12, 13, and 14 obtained 100% concordance; however, minor changes were made to these items according to the judges’ suggestions to achieve better idiomatic and conceptual equivalences. The changes were the following:

- “Likert 1” and “Likert 5”: the word “completely” was replaced by “totally”;
- “Likert 3”: the word “uncertain” was deleted, maintaining only the expression “not sure”;
- Statement 2: “I’m not shorter than people my age” was altered to “I don’t think I am shorter than people my age, that is, I think I am taller or the same height”;
- Statements 3, 5, 6, 7, 8, 9, 10, 11, 12, 13, and 14: the term “my health condition” was replaced with “my health status”;
- Statement 7: the expression “the career I would like” was replaced with “the profession I choose”;
- Statement 8: the expression “indicates that I will live” was replaced with “doesn’t stop me from living”;
- Statement 9: the words “indicates” and “physical problems” were replaced with “shows” and “health problems”, respectively;
- Statement 11: the expression “won’t” was replaced with “isn’t going to”;
- Statement 13: the term “restrict” was replaced with the word “affect”.

To ensure adaptation to the conceptual equivalence, that is, guarantee that the situations depicted or portrayed in the items truly assess the perception of the adolescents on the severity of their chronic disease, the following changes were made:

- Statement 8: the phrase “indicates that I will live” was replaced with “doesn’t stop me from living”, to clarify that this item refers to perception rather than to a clinical observation;
- Statement 12: the phrase “indicates that I’m not doing so well at school” was replaced with “doesn’t let me do so well at school”.

Only the items “Introduction 1”, “Statement 4”, and “Statement 6” did not show 100% concordance in the CVI. “Introduction 1” had an 80% concordance in the idiomatic and cultural equivalences, and a 100% concordance in the other equivalences; “Statement 4” obtained 80% in the semantic equivalence, 40% in the idiomatic equivalence, and 60% in the conceptual and cultural equivalences, while “Statement 6” obtained 80% in the conceptual equivalence and 100% in the other equivalences. These items were discussed among the members of the committee until they reached a consensus to define the pre-test version.

To ensure a better idiomatic equivalence, that is, adapt the translated item in terms of the idiomatic and colloquial expressions, the following changes were made to the instrument:

- “Introduction 1”: the terms “indicate” and “affirmations” were replaced with “mark” and “statements”, respectively;
- Statement 6: the verb “would like” was replaced with the verb “I like”.

To ensure adaptation to the conceptual equivalence, that is, guarantee that the situations depicted or portrayed in the items truly assess the perception of the adolescents on the severity of their chronic disease, the following changes were made:

- Statement 4: the phrase “I’m not” was replaced with “I don’t think I am” to show that it refers to
The order of the sentences was also changed to improve cohesion and coherence. In addition, after the pre-test stage, the suggestions of the study subjects were considered and the phrase “not so much because of puberty” was replaced with “not because of the phase of adolescence (puberty)”; reading or interpretation errors were perceived in statements 2 (33.33%), 5 (20%), 7 (13.33%), and 13 (10%). In all, the word that seemed to cause the reading or interpretation error was “no”. In some statements, the candidates stated they had not read the word “no” in the items. In other instances, even after reading the word “no”, the subjects said they had not understood the statement and suggested removing the word and putting the

In this stage, the participants reported some specific difficulties. These difficulties were:

- In Statement 4, “I don’t think I’m as well developed as people my age and it’s not so much because of puberty”, they stated that the term “puberty” was difficult to understand, and the expression “it’s not so much because of puberty”, was confusing.
- Reading or interpretation errors were perceived in statements 2 (33.33%), 5 (20%), 7 (13.33%), 11 (13.33%), and 13 (10%). In all, the word that seemed to cause the reading or interpretation error was “no”.

The pre-test was applied to a sample of 30 subjects composed of adolescent diabetic patients of both sexes, with a predominance of girls (65.52%). The average age of the subjects was 13.76 years old (standard deviation = 2.46). In all, 96.55% of the subjects were diagnosed with Diabetes Mellitus type 1 (DM1), with an average diagnosis time of 7.05 years (standard deviation = 4 years). All the subjects were being treated with insulin therapy and follow-up in primary and secondary school.

<table>
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<tr>
<th>Item</th>
<th>Semantic Equivalence</th>
<th>Idiomatic Equivalence</th>
<th>Conceptual Equivalence</th>
<th>Cultural Equivalence</th>
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<td>Statement 9</td>
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<td>Statement 10</td>
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<td>Statement 11</td>
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<td>Statement 12</td>
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<td>Statement 13</td>
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<td>Statement 14</td>
<td>1</td>
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</table>

Source: Research data, 2015.
**Items** | **Synthesis version** | **Brazilian Version after Pre-Test**  
--- | --- | ---  
**Title** | Perception of Severity of Chronic Illness (PSCI) | Perception of Severity of Chronic Illness (PSCI)  
**Introduction 1** | Indicate your answers for the following affirmations using the scale described below. | Mark your answers to the statements using the scale described below.  
**Introduction 2** | There are no right or wrong answers, because everyone is entitled to their own opinions. | There are no right or wrong answers, everyone is entitled to their own opinions.  
**Likert 1** | Completely disagree | Totally disagree  
**Likert 2** | Disagree | Disagree  
**Likert 3** | Uncertain (not sure) | Not sure  
**Likert 4** | Agree | Agree  
**Likert 5** | Completely agree | Totally agree  
**Statement 1** | I look different from people my age. | I look different from people my age.  
**Statement 2** | I’m not shorter than people my age. | I DON’T think I am shorter than people my age, that is, I think I am taller or the same height.  
**Statement 3** | My health condition is not very serious. | My health status is NOT very serious.  
**Statement 4** | I’m not as well developed (not so much because of puberty) as the people my age. | I do NOT think I am as well developed as people my age, and it’s not because of the phase of adolescence (puberty).  
**Statement 5** | My health condition doesn’t stop me from being as active as I’d like. | My health does NOT stop me from being as active (a) as I’d like.  
**Statement 6** | My health condition prevents me from practicing the sports that I would like. | My health prevents me from practicing the sports that I like.  
**Statement 7** | My health condition is not going to stop me from pursuing the career that I would like. | My health will NOT stop me from pursuing the profession I choose.  
**Statement 8** | My health condition indicates that I will live as much as other people my age. | My health does NOT stop me from living as much as other people my age.  
**Statement 9** | My health condition indicates that my physical problems will get worse over the years. | My health status shows that my health problems will get worse over the years.  
**Statement 10** | My health condition indicates that I have a lot to expect from my future. | My health status indicates that I have a lot to expect from my future.  
**Statement 11** | My health condition won’t stop me from having children. | My health status is NOT going to stop me from having children.  
**Statement 12** | My health condition indicates that I’m not doing so well at school as I could. | My health status does NOT allow me to do so well at school as I could.  
**Statement 13** | My health condition does not restrict my social life. | My health status does NOT affect my social life.  
**Statement 14** | My health condition has affected my relationship with my parents. | My health status has affected my relationship with my parents.  

**Chart 1** – Presentation of the synthesis version subjected to content validity and final version of Perception of Severity of Chronic Illness – PSCI, translated and adapted to Brazilian Portuguese. Campinas, SP, 2015  
Source: Research data, 2015.
phrase in the affirmative. To address the difficulties encountered by the adolescents, the word “no” in the referred items was typed in bold uppercase letters in the final instrument.

Chart 1 shows the synthesis version evaluated by the committee of experts and the final version obtained after the translation and adaptation of the PSCI to Brazilian Portuguese.

Regarding the practicality of the Brazilian Portuguese version of the PSCI evaluated in the pre-test phase (n = 30), the results show that 93.33% of participants agreed that the questionnaire instructions were easy to understand, 86.66% reported that they had no difficulties marking the answers of the questionnaire, and 96.66% reported they understood the questions of the questionnaire. The average time needed to complete the questionnaire was 3.49 (standard deviation = 1.12) minutes.

**Reliability**

The internal consistency of the scale was verified using Cronbach’s alpha with a sample of 29 subjects, one of which was missing and subsequently excluded. Cronbach’s alpha coefficient for the instrument (n = 29) was 0.66. Table 2 shows the reliability of each statement.

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<th>Statements</th>
<th>Correlation</th>
<th>Cronbach’s α</th>
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<td>S2</td>
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<td>S3</td>
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<td>S4</td>
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**DISCUSSION**

The aim of this study was to translate and adapt the PSCI to Brazilian Portuguese, and assess its applicability for diabetic adolescents in outpatient follow-up at a university hospital in the interior of São Paulo, Brazil.

The steps of translation, back translation, and synthesis of the PSCI were successful. In this process, the language must be culturally and conceptually adapted to the population of interest, while maintaining the goal of the original instrument. The percentage of concordance of the committee of experts was 95% of the statements with a CVI of 1.00, which is recommended in international literature for committees composed of five judges\(^\text{[12-13]}\). The face-to-face meeting between the members of the committee enabled extended discussion of all the items until concordance of the translation was reached to facilitate understanding of the instrument.

The Brazilian version of the PSCI was submitted to a pre-test to maintain the meaning of the original version, improve understanding, and detect errors and/or problems during application of the instrument that was being adapted\(^\text{[10, 19]}\). The results of the pre-test stage of the Brazilian version of the PSCI showed that, despite the changes made in the content validation stage according to the recommendation of the committee of judges, the instrument was not easily understood by the diabetic adolescents in follow-up at the university hospital. This observation led to minor changes to better adapt the instrument.

Regarding these changes, 30% of the subjects – during the pre-test – noted that statement 4 was difficult to understand, and more than half stated they did not know the meaning of the term “puberty”, which was mainly associated with “adolescence” or “something to do with adolescence”. Although the term “puberty” is not conceptually synonymous with “adolescence”, it coincides with this period in the normal development of sexual maturity. Consequently, in the Brazilian version of the PSCI, the term “puberty” was replaced with “phase of adolescence (puberty)”.

Regarding the usability of the instrument, although the vast majority believed it was easy to understand, completed the instrument within the average time (3.5 minutes), and did not have major difficulties, some interpretation problems were detected in relation to the word “no”. Therefore, we decided to highlight the term to avoid
interfering with the balance between the positive and negative statements. In the pre-test stage of the study, which sought preliminary reliability data of the PSCI, the internal consistency values of the instrument were below the desirable value (0.66), which may be related to respondents’ reported difficulties in understanding the statements, considering that the calculation of this index involves the correlations between the items of the instrument. When the items are correlated, the answers follow the same direction. If, in some items, the subjects answer in a contradictory manner, a lower correlation and, consequently, a low alpha value are expected. Another possibility is that the instrument does not specifically target diabetic adolescents, but also adolescents with cystic fibrosis.

One of the biggest challenges of the treatment of DM is patient adherence to treatment. Among the processes of diabetes care, it is important to consider the factors that hinder certain attitudes required for treatment, such as the perceptions and conceptions of the disease itself. In this regard, the present study provides the first questionnaire that assesses the perception of severity of the chronic disease DM among adolescents for use in the clinical practice and nursing research to create new therapy plans and strategic approaches that improve patient adherence to treatment.

**CONCLUSION**

The adaptation of the Brazilian version of the PSCI to Portuguese was a rigorous process that observed the recommendations of international literature. The adapted version was considered adequate in terms of its semantic, idiomatic, cultural, and conceptual equivalence, and proved practicable in relation to the average completion time.

However, so far, the obtained results were insufficient to confirm the reliability of the adapted version. We suggest new studies with patients suffering from chronic conditions, such as cystic fibrosis, and other populations of adolescents with diversified sociodemographic characteristics in treatment for diabetes mellitus.

**FINAL CONSIDERATIONS**

The limitations of this study are the non-validation of the measurement properties of the Brazilian version of the PSCI, and the absence of studies on the translation and validation of the PSCI in other cultures, which limits analysis of the methodological process.

**REFERENCES**


