Translation and cultural adaptation of the Children's Hand-Use Experience Questionnaire (CHEQ) for Brazilian children and adolescents

Tradução e adequação cultural do *Children's Hand-Use Experience Questionnaire* (CHEQ) para crianças e adolescentes brasileiros

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ABSTRACT: The Children's Hand-Use Experience Questionnaire (CHEQ) assesses how children and adolescents with asymmetric impairments such as hemiparetic cerebral palsy (CP) use their affected hand during bimanual activities on their daily routine. The CHEQ provides information about the efficiency of the affected hand, time spent and the level of discomfort felt during each activity. The aim of this study was to translate the CHEQ to Brazilian Portuguese, to assess semantic and conceptual equivalence, to adapt it culturally to the Brazilian population and to test its adequacy in a group of children/ adolescents. This methodologic study included five steps: individualized translation by two translators; unified version of the translation; backtranslation; specialists' analysis and questionnaire administration in 31 children/adolescents with hemiparetic spastic CP and their parents. Most of the participants reported no difficulties in answering any of the questions and stated that all the activities presented on the test were part of the child/adolescent's normal routine, which demonstrates cross-cultural success of the assessment tool. The Brazilian Portuguese version of the CHEQ offers an adequate tool to document children/ adolescents' experience with their affected hands during day-to-day activities, thus useful for clinical and research purposes.

KEYWORDS: Hand; Disabled children; Translating; Surveys and questionnaires; Paralysis.

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RESUMO: O Children's Hand-use Experience Questionnaire (CHEQ) avalia a experiência de uso da mão afetada em atividades bimanuais da rotina diária de crianças com comprometimento assimétrico, como paralisia cerebral (PC) do tipo hemiparesia espástica. O CHEQ informa sobre eficiência de uso da mão afetada, tempo despendido e grau de incômodo na realização das atividades. Os objetivos deste estudo foram traduzir o CHEQ para a língua portuguesa, avaliar as equivalências semântica e conceitual, adaptá-lo culturalmente à realidade brasileira e testar sua adequação em um grupo de crianças/adolescentes. O estudo metodológico incluiu cinco etapas: tradução individualizada por dois tradutores; versão unificada da tradução; retrotradução; análise de especialistas e aplicação do questionário em 31 criancas/adolescentes com PC do tipo hemiparesia espástica e seus pais. A maioria dos entrevistados relatou não ter tido dificuldade para responder a nenhuma questão e que todas as atividades representavam tarefas da rotina da criança/adolescente, demonstrando a adequação cultural do conteúdo do teste. A versão do CHEQ em português disponibiliza uma ferramenta adequada para informar sobre a experiência de crianças/adolescentes com relação ao uso rotineiro da mão afetada, podendo ser de utilidade para instrumentalizar clínica e pesquisa.

DESCRITORES: Mãos; Crianças com deficiência; Tradução; Inquéritos e questionários; Paralisia.

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INTRODUCTION

Not observe the structures and functions of one of the upper limbs, may have difficulties accomplishing these bimanual activities¹. Limitations may cause anxiety, dissatisfaction, discomfort or embarrassment³.

In the last decades, many instruments were created to evaluate the use of the upper limb during daily living activities of children with spastic hemiparetic cerebral palsy⁴. These tools measure unimanual outcomes, like the Jebsen Taylor Test of Hand Function^{5,6} and the Melbourne Assessment of Upper Limb Function^{7,8}. They evaluate, respectively, manual dexterity and movement quality during unimanual activities. Regarding to bimanual outcomes, the most used test in the literature is the Assisting Hand Assessment (AHA)⁹, which aims to evaluate the effectiveness of spontaneously using the affected upper extremity during bimanual activities, like structured play situations9. Although these instruments contribute to document the capacity to use the affected extremity, these observational tests serve only for clinical purposes, failing to observe the child in his/her natural environment¹⁰. Evidence points to children and adolescents with CP using their hands differently while at home and during rehabilitation contexts. Context-specific factors for each type of use (i.e., physical, social, attitudinal) may act as barriers or facilitators¹¹. Thus, the tools used to document the functional hand use by children and adolescents with CP should take into consideration the specificities of each context. Regarding to daily functioning at home, questionnaires aimed at parents and/or children are generally more appropriate for data collection.

Questionnaires aimed at documenting functional outcomes generally use generic tools, such as the Pediatric Evaluation of Disability Inventory (PEDI)^{12,} which assesses the level of ability and independence in daily living activities, as well as specific questionnaires focusing on bimanual activities for children with the CP, such as the ABILHAND-Kids¹⁰ questionnaire and the Children's Hand-Use Experience Questionnaire (CHEQ)¹. ABILHAND-KIDS is a questionnaire for parents, focusing on the child difficulty in performing bimanual tasks, regardless of the strategy the child adopts¹⁰. This test aims to document intervention outcomes,

not being particularly useful as a tool to develop objectives and treatment plans. It lacks details on how the affected upper extremity is used in daily living activities¹⁰. In order to develop an assessment tool for clinical and research purposes, Skold et al.¹ developed the CHEQ, which addresses the perception of caregivers/children and adolescents regarding the use of affected upper extremity during bimanual activities.

The Children's Hand-Use Experience Questionnaire (CHEQ) is an instrument that aims to evaluate hand-use in daily living activities by children with asymmetric motor impairment, such as spastic hemiparesis or OBPP¹. Data collection includes the number of activities the child performs independently, the usage of the affected upper extremity during these activities, the effectiveness of the hand use, the time required to perform each activity and the discomfort level felt by the child/adolescent during the functional performance^{1,13}. The CHEQ can be answered online by parents or guardians, with or without the presence of the child or adolescent. Adolescents over the age of 13 can answer the questionnaire by themselves¹. The items in the questionnaire follow typical day-to-day activities of children and adolescents (i.e. getting dressed, eating, using scissors). Activities were selected according to the following criteria: both hands required, high achievement relevance for a large number of people and large age range¹. After completing the CHEQ, the respondent can access a summary of the questionnaire responses and their score results¹.

The original CHEQ version was validated with 86 families, from Stockholm and Örebro, in Sweden¹. The results indicate that the tool has questions relevant to typically bimanual activities and corresponds to the age group. Arner¹⁴ reported on the internal validity of the CHEQ, as well as high reliability scales. The literature shows studies that used this questionnaire to characterize the bimanual function of children with CP¹⁵, OBPP¹⁵ and radial dysplasia¹⁶, as well as a tool for planning¹⁰ and documenting intervention impacts^{17,18}.

The CHEQ has been translated into different languages and is available in Swedish, Hebrew, Arabic, Dutch, Italian, British English, German, Spanish, Norwegian and French (CHEQ, available at www.cheq.se)¹⁹ but not in Brazilian Portuguese. The questionnaire evaluates the individuals' perception on efficiency, time required and how bothered the child is for having to use the affected hand¹⁰, is easily accessible and free. Thus, translating and cross-culturally adapting the CHEQ for Brazilian children and adolescents can be a great contribution for the assessment process on child rehabilitation.

The objectives of this study were (I) to evaluate the semantic and conceptual equivalence between the Brazilian Portuguese translated versions and the English version of the CHEQ and (II) to test the cross-culturally adaptation of the CHEQ for parents of Brazilian children and adolescents with spastic hemiparetic cerebral palsy.

METHODOLOGICAL PROCEDURES

Study design

Methodological study with two stages: (I) translation and cross-cultural adaptation; and (II) CHEQ administration (access test via: http://www.cheq.se/)¹⁹ on parents/guardians of Brazilian children and adolescents. The translation process was authorized by the instrument's original authors.

Assessment instrument: CHEQ

The CHEQ is an online questionnaire with 29 daily living activities that require the use of both hands. It is intended for parents of children and adolescents aged 6 to 18 years. Figure 1 presents the order the CHEQ questions are administrated. First, it ascertains whether the child/adolescent performs each activity by themselves. If the child/adolescent requires help, avoids the activity or their routine does not include the activity, the questionnaire guides the respondent to the following activity. If the child/adolescent manages the activity without help, it questions how the activity is performed. The following options are available: (a) with one hand; (b) with both hands, the involved hand supporting without holding; (c) with both hands, the involved hand holding the object. Then, if the child/adolescent accomplishes the activity with both hands, the respondent is asked to use a numerical scale – ranging from 1 to 4 points –, to evaluate: (a) how effective is the grasp/support, ranging from 1 = noteffective to 4 = effective; (b) how much time the child needs for the whole task to be completed, compared to his peers, ranging from 1 = considerably longer to 4 = equally long; (c) if the child is bothered by his/her reduced hand/arm function during the activity, ranging from 1 = it bothers him/her a lot to 4 = it does not bother him/her at all. If the child uses only one hand to perform the activity, the respondent is asked to use the same numerical scale described above to evaluate the items: time spent performing the activity in relation to their peers and how bothered the child is when using the affected hand in the activity. An example of the questions and the response options for the items of the questionnaire can be observed in Figure 2.

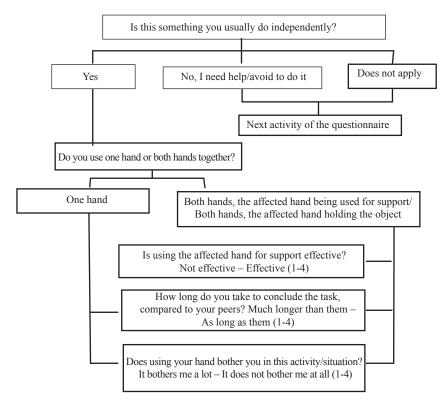


Figure 1 - CHEQ questions according to order of presentation

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Figure 2 – Sample questions and options for answering the CHEQ items.

Procedures

Translation process and cultural adaptation

The translation procedures and cross-cultural adaptation followed the proposal described by Beaton et al.²⁰. The process involved five stages: translation of the original version by two independent translators, creation of an unified version of the translation, back-translation, culminating on a pre-final translation and ending with the administration of a translated and adapted version for the development of the final version.

In the first stage, two Brazilian individuals fluent in English independently translated the English version of the CHEQ into Brazilian Portuguese. In the second stage, the independent translators met with an intermediary, also fluent in English, in order to compare the two translated versions and develop a third version, reconciling discrepancies between the first two versions. In the third stage, an individual who has English as his first language, but has lived in Brazil for ten years and did not know the original version of the CHEQ in English, performed the back-translation of the third version. This person was instructed to perform this translation observing the original meaning of the text. The back-translated version was then compared to the English version of the CHEQ by a team of two professionals specialized in children, with experience abroad and fluent in English. The result of this comparison was a pre-final version of the translation, which was then administered to parents and/or guardians of children and adolescents previously selected for the study.

Administration of the questionnaire

Thirty-one children and adolescents with spastic hemiparetic cerebral palsy, between the ages of 6 and 18 years, and their parents participated in the study. The participants answered the items of the pre-final translated version of the CHEQ. The sample was recruited by convenience at the *Associação Mineira de Reabilitação* (AMR) in the city of Belo Horizonte/MG, by surveying diagnostic data from the institution's medical records. The principal researcher was responsible for this survey. The sample size followed the recommendations of Beaton et al.²⁰, who suggested a sample size of 30 to 40 individuals for administering the test and for the subsequent cross-cultural adaptation. The age of the children/adolescents was limited by the age range of the test.

This study was approved by the Research Ethics Committee of the University Hospital São José (ETIC 23 100313.1.0000.5134). Data collection occurred from January to July 2014. Firstly, parents/guardians and children/adolescents with CP were contacted individually at the AMR right after the rehabilitation visits and were told about the study's aim and procedures, possible risks and benefits. After reading the Informed Consent Form (ICF), the parents and children/ adolescents who agreed to participate in the study, were asked to sign the ICF. The CHEQ administration occurred at AMR, individually, in a room equipped with a computer. All parents answered the CHEQ on the computer. Throughout this time, a single evaluator was present in case the parents/guardians had any doubts. For children between six and 12 years old, only the parents/guardians answered the CHEQ. For adolescents, on the other hand, participants and their parents/guardians answered the questionnaire together.

After the CHEQ administration, parents and adolescents were asked to answer previously structured questions about the clarity of understanding and appropriateness of the CHEQ, which sought to identify possible difficulties in understanding any of the test questions and whether the activities listed in the CHEQ were actually day-to-day activities of the child/adolescent. Parents/ guardians also answered a socioeconomic questionnaire of the Brazilian Association of Research Companies (ABEP) (*Associação Brasileira de Empresas de Pesquisa*, Economic Classification Criteria Brazil-2012), available at: www. abep.org)²¹ for a socioeconomic characterization of the sample. This classification estimates the purchasing power of

 Table 1 – Adaptations used in the translated version of the CHEQ

Brazilian families, divided into socioeconomic strata that vary from class A1 to E, with intermediate classifications, totaling 8 possible classes. This classification is obtained through data regarding household items (e.g. television, car, refrigerator) and the head of household's schooling²¹.

Data analysis

During the CHEQ translation process, conceptual and semantic equivalences between the original and the Brazilian Portuguese versions were analyzed, using a comparative table. We used descriptive statistics, with a frequency index, to characterize the children/adolescents and their parents or guardians, taking into account age, gender, socioeconomic level and parents/guardians' schooling. Frequency indexes were also used to analyze data from the CHEQ administration and the questions regarding understanding and appropriateness of the test.

RESULTS

During the CHEQ translation process, we identified some discrepancies between the English version and the prefinal Brazilian Portuguese version. Ten out of the 29 items of the questionnaire required some kind of cross-cultural adaptations and examples, besides addition, omission or substitution of words to improve understanding. Table 1 shows items in both English and Brazilian Portuguese, specifying adaptations when they occurred, as well as the type of adaptation.

ORIGINAL	PRE-FINAL TRANSLATION	TYPE of ADAPTATION
Pull up track suit trousers	Veste calças com elástico na cintura	Cultural substitution
Butter a slice of soft bread	Passa manteiga em uma fatia de pão	Omission of words
Cut up a pancake (or other food easy to cut up) on the plate	Corta omelete (ou outro alimento fácil de cortar) em um prato	Cultural substitution
Cut on a chopping board (for example fruit, vegetables, bread)	Corta alimento em uma tábua de cortar (por exemplo, fruta, vegetais e pão)	Cultural substitution
Remove a straw from the front of a juice box and insert it. (Refers to the whole process, including taking off the wrapping of the straw)	Retira o canudo afixado na frente de uma embalagem de suco e o insere no local adequado (Refere-se a todo o processo, incluindo a retirada da embalagem do canudo)	Addition of words
Remove the wrapping from an ice-cream	Remove a embalagem de um picolé	Cultural substitution
Remove the wrapping from a piece of candy	Abre a embalagem de um bombom ou bala	Cultural substitution, Addition of words
Take off the protective plastic backing of a Elastoplast	Remove o papel protetor de um curativo adesivo (por exemplo, band-aid)	Explicitation
Fasten a necklace (whilst around the neck)	Abotoa o fecho de um colar (que está no pescoço)	Addition of words
Handle playing-cards (Refers to the whole process; holding, selecting and placing cards in the hand while playing)	Manipula cartas de baralho (refere-se a todo o processo: segurar, selecionar e posicionar as cartas na mão enquanto joga)	Substitution of words

Among the sub-questions of the CHEQ, only the question "How effective is the grasp/support?" differed in the Brazilian Portuguese version. The translation changed how the question is asked: "*A preensão ou o uso da mão para suporte é efetivo*?" (basically: "Is the grasp or use of the hand for support effective?"). Two response options also differed from the English questionnaire. The answer "effectively" was translated in to "*efetivo*" and "ineffectively" became "não efetivo", showing a disparity not in content but in word class used (adverb and adjective, respectively).

Thirty-one children/adolescents and their parents participated in the evaluation process to check for crosscultural appropriateness of the translated CHEQ. Of the respondents, 90.3% were mothers, 6.5% were grandparents and 3.2% were fathers. The descriptive characteristics of the children and adolescents, whose parents and/or guardians answered the pre-final translated version of the CHEQ are listed in Table 2.

Of the parents/guardians, 93.6% (n = 29) of the interviewees reported having no difficulty understanding the CHEQ items. Only one respondent reported difficulty in understanding the following questionnaire item: "take off the protective plastic backing of an Elastoplast (for example, a band-aid)"; he claimed not to know what a band-aid or Elastoplast was. After an explanation and viewing the respective drawing, the respondent understood and was able to answer the item with clarity. Another interviewee reported difficulty understanding the meaning of the word "effective" in one of the sub-question of the questionnaire and required further explanation to proceed. Among adolescents older than 12 years, no one reported any difficulties understanding the CHEQ questions and they all identified the activities listed in the questionnaire as being part of their routines. After the pre-final version was administered, no need for further translation changes was identified.

Descriptive Variables		Sample (N=31)	
Gender of the children/ adolescents	Male Female	16 (51.6%) 15 (48.4%)	
Age of the children/ adolescents	6 to 12 years 13 to 18 years	22 (71.0%) 09 (29.0%)	
Socioeconomic status of the families (ABEP) ¹	Categories of the Brazil Economic Classification Criteria	A1/A2 = 1 (3.2%) B1/B2 = 13 (42%) C1/C2 = 17 (54.8%)	
Parents/guardians education	Brazil Economic Classification Criteria	Incomplete Elementary School = 1 (3.2%) Complete Elementary/Incomplete Middle School =11 (35.5%) Complete Middle School/Incomplete High School =5 (16.1%) Complete High School/Incomplete Undergraduate Study =10 (32.3%) Complete Undergraduate Study = 4 (12.9%)	

Table 2. Descriptive characteristics of children and adolescents, parents and families

¹ABEP= Associação Brasileira de Empresas de Pesquisa (Brazilian Association of Research Companies)²¹

DISCUSSION

Assessment instruments capable of describing, characterizing and evaluating the functional impact of upper limb asymmetric conditions are important in Occupational Therapy and its evaluation processes^{2,22}. Using the same instrument in different countries requires a translation process and cross-cultural adaptation for it to be suitable for use²³. The translation method and cross-cultural adaptation of self-evaluation questionnaires into

other languages should be standardized and follow specific and pre-established stages, in order to produce a translated version that is faithful to the original version^{20,24}.

In order to meet the criteria above and thus obtain an adequate version of the CHEQ instrument in Brazilian Portuguese, we used a translation adequacy method already established²⁰, internationally recognized²⁰ and used by other authors^{22,25}.

During the translation process of the CHEQ, there were some discrepancies between the original version and

the translated version, which required semantic, conceptual and cross-cultural adaptations to the Brazilian population. For example, the item "pull up track suit trousers" was translated to "veste calças com elástico na cintura", thus a cross-cultural adaptation was necessary, since Brazilian track suit trousers do not always have elastic waists. Another item that demanded cultural adaptation was "cut up a pancake (or other food easy to cut up) on the plate", which was translated to "corta omelete (ou outro alimento fácil de cortar, em um prato)". In Brazil, pancakes are not regularly consumed, so the term was replaced by omelet, due to its similar texture and consistency, and because it is a food Brazilians eat regularly. Lastly, the item "remove the wrapping from a piece of candy", was translated to "abre a embalagem de um bombom ou bala", which is a crosscultural adaptation, since sweet is generic (piece of candy) and in Brazil, only bonbons and candies are usually sold in units. Besides the cross-cultural adaptation, we also had to add words, citing more than one example (candy or bonbon), which in English was accomplished with a single term to specify the type of sweet (piece of candy). All these changes were previously discussed and authorized by the authors of the original CHEQ.

The need for word addition was also identified in the items "cut on a chopping board (for example fruit, vegetables, bread)", translated to "corta alimento em uma tábua de cortar (por exemplo, fruta, vegetais e pão)", "remove the straw from the front of a juice box and inserts it (refers to the whole process, including taking off the wrapping of the straw)", translated to "retira o canudo afixado na frente de uma embalagem de suco e o insere no local adequado (refere-se a todo o processo, incluindo a retirada da embalagem do canudo)" and "fasten a necklace (whilst around the neck)", translated to "abotoa o fecho de um colar (que está no pescoço)". The addition of the words food (in the item referring to the cutting board), appropriate slot (in the item referring to the removal of the straw from a juice box) and clasp (in the item referring to the claps of the necklace) were necessary to improve understanding, since they better characterize the actions described.

Besides addition of words and examples, we also had to omit or replace words in some items, in order to avoid strangeness of terms not commonly used in Brazilian Portuguese. In the item "butter a slice of soft bread", translated to "*passa manteiga em uma fatia de* $p\tilde{a}o$ ", the word "soft" was removed once this emphasis is unnecessary for the types of breads typically found in Brazil. In the item "take off the protective plastic backing of a Elastoplast", translated to "*remove o* papel protetor de um curativo adesivo (por exemplo, Band-aid)", the term Elastoplast was replaced by "curativo adesivo" (adhesive dressing), since this term is unknown in Brazil, being a brand name. For further clarity, we added an example (Band-aid), a brand name more popularly known in this country. The word "handle", present in the item "handle playingcards (refers to the whole process; holding, selecting and placing cards in the hand while playing)", was translated to "manipula cartas de baralho (refere-se a todo o processo: segurar, selecionar e posicionar as cartas na mão enquanto joga)". When translated wordfor-word, the verb "handle" in Brazilian Portuguese means "to deal". However, since in Brazil the verb "lidar" (to deal) is not commonly associated with the task of manipulating playing cards, we found the word "manipular" (manipulate) more appropriate, since it implies the use of hands.

Regarding the conceptual equivalence between the original and the translated versions of the CHEQ, we made some adaptations on the use of the word "remove" and its literal translation "remover". In English, this same word has been properly used in the description of various items (i.e. Remove a straw from the front of a juice box and insert it; Remove the wrapping from an ice-cream. Remove the wrapping from a piece of candy). In Brazilian Portuguese, other words better express the actions described above. Thus, the term "remove" was only translated word-for-word in the item "Remove a embalagem de um picolé". It was replaced with the words "retira" (withdraw) in the item "Retira o canudo afixado na frente de uma embalagem de suco e o insere no local adequado" and "abre" (open) in the item "Abre a embalagem de um bombom ou bala", in order to improve understanding by the local population.

There was also a change on the way used in one of the CHEQ sub-questions, "How effective is the grasp/support?", which was translated to "*A preensão ou o uso da mão para suporte é efetivo?*". In English, the word "How" indicates intensity of action, implying quantification. Thus, the respondent is asked to score from one to four the effectiveness of the action. In Brazilian Portuguese, the question offers two options: yes or no, disregarding the idea of quantifying the effectiveness of the action. Only one mother of a child participating in the study reported difficulties with answering this question. Thus, the question remained as it was originally translated. The answers "effectively" and "ineffectively" translated, respectively, to "*efetivo*" (effective) and "*não efetivo*" (not effective), we saw the need to change the word class from adverb (indicating intensity of action) to adjective.

CONCLUSION

Translating the CHEQ into Brazilian Portuguese may contribute to a more detailed evaluation of the hand use of children and adolescents with impairments in their upper extremity function, with utility for both clinical and research purposes. The final version of the questionnaire in Brazilian Portuguese is suitable for Brazilian children and adolescents, with more than 90% of respondents having no difficulties answering the questionnaire. This percentage is superior to the recommended for cultural adequacy of instruments (above 80%²⁶). CHEQ is already available in several languages and this fact reinforces the cross-cultural importance of this instrument for pediatric rehabilitation.

Authors' note: In 2016, during the submission process and manuscript evaluation, the CHEQ authors published the new CHEQ version 2.0 (updated version) and the Mini-CHEQ (a version for younger children, from 3 to 8 years old). The two new versions of this test are already available in Portuguese, at www.cheq.se.

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