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Translation and cultural adaptation of the Health Utilities Preschool to Brazilian Portuguese

Karina Viani [a,*], *Bruno Fernandes Bernardes* [b], *Marilia Nasz Veiga* [b], *Renato Canton Viani* [b], *Tomas Marzagão Barbuto* [a], *Ronald D. Barr* [c]

[a] *Instituto de Tratamento do Câncer Infantil (ITACI), Instituto da Criança e do Adolescente, Hospital das Clínicas, Faculdade de Medicina, Universidade de São Paulo, Brazil*
[b] *Independent researcher, Brazil*
[c] *Professor Emeritus, McMaster University, Canada*

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ABSTRACT

Introduction: Health research is particularly important in low- and middle-income countries (LMICs), where improvements must be achieved with limited resources, and where the great majority of the world's population, especially children, live. Improvements in public health detection in Brazil have resulted in cancer becoming the most prevalent cause of death by disease in the group aged 1 to 19 years, hence, delivering cost-effective care to the group is a priority. Preference-based measures of health status and health-related quality of life (HRQL) integrate morbidity and mortality and provide utility scores for the estimation of quality-adjusted life years to be used in cost-effectiveness analyses and economic evaluation. The generic preference-based instrument Health Utilities - Preschool (HuPS) measures the health status of young children and is applicable to the age group 2 to 5 years, who carry the highest incidence of cancer in childhood.

Methods: The translation of the HuPS classification system followed recommended protocols from published guidelines. Forward and backward translations were performed by a team of six qualified professionals and linguistic validation was undertaken with a sample of parents of preschool children.

Main results: Initial disagreements on individual words occurring in 0.5-1.5% were resolved by consensus. A final version of the instrument was validated by the sample of parents.

Conclusions: The translation and cultural adaptation of the HuPS into Brazilian Portuguese were accomplished as the first step in the validation of the HuPS instrument in Brazil.

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Introduction

Health research is an essential tool for advancing health and development, both for applying available solutions and for creating new knowledge for unsolved problems. Moreover, it

Abbreviations: HRQL, health-related quality of life; HuPS, health utilities – preschool; QALYs, quality-adjusted life years; CHSCS-PS, comprehensive health status classification system-preschool

* Corresponding author at: Rua Galeno de Almeida, 148 - Pinheiros, São Paulo SP, Brazil.
E-mail address: karina.viani@hc.fm.usp.br (K. Viani).

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is an important link to equity in development, as it promotes acceleration of health improvements, reducing health disparities worldwide.[1,2]

Health research is particularly imperative in low- and middle-income countries (LMICs) because these are where the great majority of the world's population, especially children,[3] live and where health improvements must be achieved with limited resources.[1,2] In nations with emerging economies, improvements in public health result in diminishing importance of infection and malnutrition as causes of death in childhood. For instance, as in high income countries, in Brazil cancer currently represents the most prevalent cause of death by disease in children and adolescents aged 1 to 19 years old, with 12,500 new diagnoses every year.[4] Delivering cost-effective care to this sub-population is an obvious high priority and attaining this goal in low- and middle-income countries (LMICs) has been demonstrated, although the issue of affordability remains a challenge.[5]

To evaluate the quality and quantity of health care services, it is essential to measure health-related quality of life (HRQL), both in general and clinical populations.[6] The HRQL is a general, multi-dimensional and dynamic construct influenced by physical, psychological and social functioning.[6] There are few methods available for the HRQL measurement in preschool children, considered to be the most important phase of human development,[7] and they are all health profiles.[8] By definition, these do not provide utility scores. Instruments which use a preference-based approach have the advantages of providing utility scores for individual subjects. Preference/utility scores are measured, unlike values, under conditions of uncertainty, as is the case of health. Utilities are especially useful to integrate effects of both morbidity and mortality, or, in summary, measures, such as quality-adjusted life years (QALYs). Furthermore, utilities and QALYs are important metrics in cost-effectiveness/utility analyses, which inform decision-making professionals about the distribution of scarce health care resources.[9] The measurement of the HRQL can be very challenging in clinical pediatrics, especially in preschool-aged children, given the rapidity of developmental changes and the need for proxy assessment.[10] Generic multi-attribute utility measures are suitable for use in the general population and in groups with specific clinical conditions. Those developed for older children are the 16D [11] and 17D,[12] the Health Utilities Index Mark 2 (HUI2),[13] the Health Utilities Index Mark 3 (HUI3),[14] the European Quality of Life 5-Dimension Youth version (EQ-5D-Y),[15] the Assessment of Quality of Life 6-Dimension (AQoL-6D) [16] and the Child Health Utility 9D (CHU-9D).[17] Only HUI2, HUI3 and EQ-5D-Y can be used by proxy respondents who are commonly parents, in the case of young children.

The Comprehensive Health Status Classification System-Preschool (CHSCS-PS) is a multi-dimensional tool for measuring comprehensive health status in young children. The CHSCS-PS evolved from the well-established Health Utilities Index (HUI) systems for subjects 5 years of age and older.[18] The CHSCS-PS has been described previously [19] and its measurement properties assessed in studies of both community and clinical populations, with reliability, content and construct validity, and inter-observer agreement established in a large community sample,[20] as well as in children with cancer.[10] The CHSCS-PS forms the basis of the generic preference-based instrument Health Utilities-Preschool (HuPS), applicable to children 2 to 5 years of age.[21]

Our group of investigators is focused on cancer in children and has recognized the need for a utility-based HRQL instrument for use in this population in Brazil for over a decade.[22] The translation of some HUI instruments into Brazilian Portuguese has been undertaken previously by members of our group.[22,23] The remaining need is for a HUI-based instrument suitable for preschoolers, which will be enabled by the earlier work. It is important to recognize that the incidence of cancer in childhood is highest in the first 5 years of life.[24] Thus, this study performed a formal linguistic and cultural translation of the HuPS classification system from its original form (English) to Brazilian Portuguese.

Materials and methods

The HuPS classification system has 8 domains/attributes of health, each with 4 to 6 levels of function. One level for each domain/attribute constitutes an 8-element vector which describes a comprehensive health state. A compound "disability score" can be calculated as the sum of the levels.[23] The classification system was translated and adapted by a team of 6 qualified professionals, being 2 females and 4 males. Forward and backward translations were performed by native Brazilian Portuguese speakers with at least a bachelor's degree, who were also fluent in the English language. The translation followed recommended protocols from published guidelines [25,26] and the corresponding author (KV) served as the project manager. The translation and cross-cultural adaptation comprised the following steps:

1) two independent forward translations of the original document, from English to Brazilian Portuguese (T1 and T2: authors MNV and BFB);

2) a third person (author KV) combined the two translated versions into a Brazilian Portuguese consensus version;

3) two independent back translations of the Brazilian Portuguese consensus version to the original language (T3 and T4: authors RCV and TMB) and the translators did not have access to the original documents or any related information other than the translated texts;

4) review and compiling of the English back translations by a native English speaker and experienced quality-of-life researcher (author RDB, who is a co-developer of the HUI), with a later comparison to the original document;

5) final revision and formatting of the Brazilian Portuguese version;

6) linguistic validation, as was undertaken in the translation of the HuPS into Canadian French, and; [27]

7) the whole process was supervised by another of the developers of the HUI family of instruments (William Furlong), as was done previously.[23]

The linguistic validation was carried out through face-to-face cognitive debriefing interviews with a convenience sample of employees at a university hospital in São Paulo, Brazil who were parents of healthy children aged 2 to 5 years old. If the parents had more than one child in this age group, they were asked to think about their youngest child when

providing feedback on their understanding of the instrument. All participants were asked in Brazilian Portuguese about their level of education and to read a copy of the Brazilian Portuguese HuPS. Then, they were asked to answer a series of open-ended questions about the instructions, questions and response options. The questions were: 'Do you understand the instructions of this instrument? Do you understand the response options? Did you have any difficulties with the instrument? If so, how would you rephrase the instructions/responses? Any other comments or suggestions about the instrument?'. The answers provided orally by the participants were summarized by the interviewer (author KV). Suggestions and comments related to the translated instrument were reported and reviewed by the project managers (authors KV and RDB). Proposed changes to the instrument will be adopted when a consensus is established with the original HuPS developers, as was undertaken with the Canadian French linguistic validation.[27] Information on the use of the HuPS instrumentation, including scoring instructions, may be obtained from the Health Utilities Inc. at http://healthutilities.com.

Results

Table 1A shows the key word discrepancies between translators 1 and 2 and finalized words from the forward translation process. Table 1B shows the equivalent results from the back translation process. These exercises resulted in initial disagreements for 12 of 845 words (1.4%) for the forward translation and 6 of 812 words (0.7%) for the back translation, the denominator being the sum of nouns, verbs, adjectives and adverbs in the classification system. The discrepant terms were reconciled by the translators and the project manager, who reached a consensus on which were the most appropriate Brazilian Portuguese words, semantically and culturally, within the specific contexts. The final Brazilian Portuguese version of the HuPS is shown in Table 2.

The linguistic validation was conducted with 21 participants, 2 men and 19 women, of whom 6 (29%) had completed secondary education, 11 (52%), higher education, and 4 (19%), a graduate degree. All participants (100%) reported that they clearly understood the instructions and responses, did not have difficulties understanding the Brazilian Portuguese that was used and some made minor comments and suggestions to further improve the understanding of the instrument.

Table 1A – Forward translation discrepancies between translators 1 (T1) and 2 (T2).

T1	T2	Final word
Capacidade	Habilidade	Capacidade
Ouvir	Escutar	Escutar
Barulho	Ruído	Ruído
Calmo	Silencioso	Silencioso
Língua	Idioma	Idioma
Discurso	Fala	Fala
Ajuda	Assistência	Ajuda
Emoção	Sentimento	Emoção
Pensar	Raciocinar	Pensar
Resolver	Solucionar	Solucionar
Maioria	Quase todas	Maioria
Joga	Brinca	Brinca

Table 1B – Back translation discrepancies between translators 3 (T3) and 4 (T4).

T3	T4	Original key word
Listen	Hear	Hear
Common	Normal	Normal
Bends	Turns	Bends
Raises	Gets up	Lifts
Disinterested	Uninterested	Uninterested
Day-to-day	Daily	Daily

Discussion

Our paper describes the process used to translate and adapt important HRQL tools, based on the HUI, for use with preschool-aged children in Brazil. The widely utilized HUI2 and HUI3 instruments are appropriate for assessing the health of older children (and adults).[19] Indeed, the HUI3 is the most frequently used generic, preference-based measure of HRQL in children.[28] Instruments in the HUI inventory include 16 versions of HUI questionnaires in the English language and many of these are available in other languages, including Brazilian Portuguese, for the measurement of the HRQL in survivors of cancer in childhood who were old enough (aged more than 13 years) to self-complete the questionnaires and, thus, to self-report on their health status.[22,23] The quality of the translation was assessed by acceptability, face validity, interrater reliability and convergent validity using patients, as well as physician and nurse proxy respondents.[22] That study was conducted by the *Grupo Especializado em Pediatria dos Efeitos Tardios do Tratamento Oncologico (GEPETTO)* at the *Centro de Tratamento e Pesquisa of Hospital AC Camargo* in São Paulo. The *GEPETTO* is a multi-disciplinary team established to follow, monitor and treat long-term cancer survivors. For the study, these included survivors of acute leukemias, malignant lymphomas, malignancies of the central nervous system and extra-cranial solid tumors. Of the 138 subjects, one-third reported cognitive disability or pain and one quarter reported problems with vision, speech or emotion, results similar to those reported in other countries, including those in Central and South America, using the HUI instruments.[23] The CHSCS-PS (a forerunner of the HuPS) in English has been used in a community sample of 4,546 preschool children in the Netherlands,[20] in which good discriminant validity was demonstrated, as well as among infants with very low birth weight,[29] children with cerebral palsy [29] and children with solid tumors.[10,30] A strength of this instrument is that it can identify almost 40 million different health states, based on a factorial of the number of domains/attributes and the number of levels.[22]

Conclusions

The translation and cultural adaptation of the HuPS classification system into Brazilian Portuguese is the first step in the

Table 2 – Brazilian Portuguese version of Health Utilities Preschool Classification System (HuPS).

Visão: conceito de medição: capacidade de enxergar Enxergar "de perto" está ao alcance do braço; ver "a uma distância" significa o outro lado da rua. "Objetos pequenos" significa tão pequeno quanto um polegar
1. Enxerga normalmente sem óculos (por exemplo, capaz de enxergar o suficiente para reconhecer objetos pequenos perto de si mesma e pessoas familiares do outro lado da rua). 2. Enxerga normalmente com óculos (por exemplo, capaz de ver o suficiente para reconhecer objetos pequenos perto de si mesma e pessoas familiares do outro lado da rua). 3. Enxerga bem o suficiente para reconhecer pequenos objetos perto de si mas não consegue reconhecer pessoas familiares do outro lado da rua. 4. Enxerga bem o suficiente para reconhecer as pessoas familiares do outro lado da rua, mas incapaz de reconhecer objetos pequenos perto de si mesma, mesmo de óculos. 5. Não é consegue enxergar o suficiente para reconhecer objetos pequenos perto de si mesma ou pessoas familiares do outro lado da rua, mesmo de óculos. 6. Não enxerga nada.
Audição: conceito de medição: capacidade de escutar
1. Escuta o que uma pessoa está dizendo em um ambiente comum com ruído de fundo e distrações, sem um aparelho auditivo. 2. Não consegue escutar o que uma pessoa está dizendo em um ambiente comum com ruído de fundo e distrações, mas capaz de escutar o que uma pessoa está dizendo em um ambiente silencioso quando não há distrações concorrentes, sem um aparelho auditivo. 3. Escuta o que uma pessoa está dizendo em um ambiente calmo quando não há distrações concorrentes, mas requer um aparelho auditivo para fazê-lo. 4. Incapaz de escutar o que uma pessoa está dizendo, mesmo em um ambiente calmo e com um aparelho auditivo. 5. Não escuta nada.
Fala: conceito de medição: capacidade de articular-se claramente (e não a habilidade de usar o idioma em si)
1. Fala claramente e é entendido por todos. 2. Fala compreendida pelos pais, mas apenas compreendia parcialmente por outros. 3. Fala compreendida parcialmente tanto pelos pais quanto por outros. 4. Não fala ou faz apenas sons monossilábicos / ininteligíveis (inclui sons entendidos pelos cuidadores).
Deambulação: conceito de medição: capacidade de se locomover. Equipamento mecânico: bengalas, muletas, aparelhos de proteção, cadeira de rodas / carrinho de criança, empurrar brinquedo / andador, inclui segurar na parede / mobiliário para suporte - não inclui órteses de tornozelo
1. Caminha, se curva, levanta, salta e corre, assim como outros da mesma idade. 2. Anda, se curva, levanta, salta ou corre com algumas limitações, mas não requer equipamentos mecânicos ou a ajuda de outra pessoa para se locomover independentemente (por exemplo, um caminhante desajeitado e independente). 3. Caminha ou passa sem qualquer ajuda de outra pessoa, mas requer equipamento mecânico (este nível inclui engatinhadores/rastejadores independentes). 4. Não é possível caminhar ou passar sem a ajuda de outra pessoa e também pode exigir equipamento mecânico (por exemplo, carrinho de criança).
Destreza: conceito de medição: capacidade de executar tarefas finas de coordenação. Capacidade de usar ambas as mãos para brincar, alimentar-se, auxiliar no vestuário e na roupa. As "ferramentas especiais" incluem: órtese especial; Colheres, garfos ou copos adaptados; aros no zíper; pegadores de espuma em marcadores / pincéis
1. Uso completo de ambas as mãos e dez dedos. 2. Limitações no uso de mãos ou dedos, mas não requer ferramentas especiais ou ajuda de outra pessoa (inclui: lento, estranho, mas independente). 3. Limitações no uso de mãos ou dedos, requer a ajuda de outra pessoa para algumas tarefas (não é independente, mesmo com o uso de ferramentas especiais). 4. Limitações no uso de mãos ou dedos, requer a ajuda de outra pessoa para todas as tarefas (não independente mesmo com o uso de ferramentas especiais).
Emoção: conceito de medição: frequência de sofrimento emocional
1. Geralmente alegre e interessado nas atividades diárias. 2. Ocasionalmente irritável, inquieta, infeliz ou desinteressada nas atividades diárias. 3. Muitas vezes irritável, inquieta, infeliz ou desinteressada nas atividades diárias. 4. Sempre ou quase sempre irritável, inquieta ou infeliz e geralmente desinteressada nas atividades diárias.
Cognição: conceito de medição: capacidade de pensar e entender como resolver os problemas do cotidiano. Problemas diários, ex. obtendo um biscoito, bebida derramada - precisa reconhecer um problema e gerar possíveis soluções; seguir uma instrução de dois passos
1. Capaz de pensar e entender como solucionar problemas do dia a dia tão bem quanto outros da mesma idade. 2. Tem um pouco mais de dificuldade do que as outras na mesma idade ao tentar pensar e entender como resolver problemas diários. 3. Tem muito mais dificuldade do que as outras na mesma idade ao tentar pensar e entender como resolver os problemas do cotidiano. 4. Incapaz de pensar e compreender como resolver os problemas do dia a dia.
Dor e desconforto: conceito de medição: frequência de dor e interrupção de atividades
1. Livre de dor e desconforto (por exemplo, geralmente não tem dor de ouvido, constipação, dor de dente). 2. Dor ocasional, sem interferência nas atividades normais. 3. Dor frequente que interfere na maioria das atividades normais. 4. Dor constante que interfere em todas as atividades normais.

validation of the instrument in Brazil. This will make it possible to measure the HRQL of preschool-aged children in Brazil with a generic preference-based instrument. This instrument will be useful in the other 9 countries in which Portuguese is an official language, the majority of which are in Africa, and it will be especially useful for preschoolers with cancer, as the incidence of malignant disease in children is highest in the first 5 years of life.[24]

Conflicts of interest

The authors have no competing interests to declare.

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