Translation and cultural adaptation of Peds QL™ ESRD to Portuguese

Tradução e adaptação cultural do Peds QL™ ESRD para a língua portuguesa

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Submitted on: 07/11/2011
Approved on: 09/26/2011

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This study was undertaken at the Unidade de Nefrologia Pediátrica do Instituto da Criança do HC/FMUSP.

The authors report no conflict of interest.

ABSTRACT

Objective: To translate into and adapt to Brazilian Portuguese the Peds QL™ – End Stage Renal Disease version 3.0 questionnaire. **Method:** The methodology proposed by the creator of the original questionnaire was adopted. It consisted of 4 phases: translation from English into Brazilian Portuguese, back-translation into English, application to a population sample and proof-reading and completion. The translations and review were made by professional experts in Portuguese and English. The questionnaires were composed of versions for children and adolescents` reports and parents` reports, and were divided according to age ranges: 2-4 years (parents` report only), 5-7 years, 8-12 years and 13-18 years. 35 interviews were conducted with 15 children and adolescents and 20 carergivers. **Conclusions:** The process of translation and cultural adaptation, which consisted of semantic equivalence (equivalence between words), idiomatic equivalence (no equivalent expressions found or items that needed to be replaced) and experimental equivalence (words and situations appropriate to the Brazilian cultural context), resulted in a version that was understandable and easy to apply.

Keywords: Quality of Life. Questionnaires. Child. Renal Insufficiency.

RESUMO

Objetivo: Traduzir e adaptar a versão 3.0 do questionário Peds QL™ – *End Stage Renal Disease* para a língua portuguesa. **Metodologia:** A metodologia adotada foi proposta pelo idealizador do questionário original e é composta por 4 fases: tradução da versão original, retradução para o idioma inglês, aplicação em grupos de pacientes e prova de leitura e finalização, sendo que, as traduções e a revisão foram realizadas por profissionais especialistas nas línguas portuguesa e inglesa. Os questionários são compostos pelas versões de relato da criança e do adolescente e relato dos pais, e divididos em faixas etárias de 2 a 4 anos (apenas relato dos pais), 5 a 7 anos, 8 a 12 anos e 13 a 18 anos. Ao todo, foram realizadas 35 entrevistas, sendo 15 de crianças e adolescentes e 20 dos responsáveis. **Conclusões:** O processo de tradução e adaptação cultural, que consistiu na equivalência semântica (equivalência entre as palavras), equivalência idiomática (expressões equivalentes não encontradas ou itens que precisavam ser substituídos) e equivalência experimental (palavras e situações adequadas ao contexto cultural brasileiro), resultaram em uma versão de fácil compreensão e administração.

Palavras-chave: Qualidade de Vida. Questionários. Criança. Insuficiência Renal.

INTRODUCTION

Technology has increased the survival of a large number of children with chronic diseases. Living with the disease, having to attend periodical outpatient follow-up and being regularly admitted to hospital impact on the routine of the child and family, making childhood and adolescence very different from those of healthy subjects.[1-7]

The care of a child with chronic renal disease (CRD) has peculiarities that may change the family routine and the patient`s social insertion, chiefly the ones related to special dietary needs, chronic daily use of multiple medications and susceptibility to frequent clinical complications.[8] Furthermore, dialysis access must sometimes be obtained, with consequent changes to the patient`s physical looks, either because of a Tenckoff`s catheter in the abdomen or an arteriovenous fistula, generally in the upper limbs. These patients thus become highly dependent on their caregivers, with important repercussions on their quality of life (QL) and that of their families.[9-18]

School years and adolescence are characterized by intense group activity. Patients with end-stage renal disease (ESRD) or advanced-stage renal disease (ASRD) may develop antisocial behavior out of fear of peer discrimination, due to physical changes brought about by their clinical conditions. In order to improve the QL of ASRD patients, it is thus important to make therapeutic decisions that take into account the several features of the individual patient, such as: age, lifestyles, housing conditions and socioeconomic status.[19-24]

As defined by the World Health Organization (WHO), QL should consider the individual`s subjective perception of his or her well-being.[2,25-28] Yet, the use of generic instruments makes it difficult to accurately measure the QL of the individual patient. The use of specific instruments is then an attempt to measure each patient`s actual perception of his or her condition.[22,29-31] Although there are specific instruments to assess the QL of ASRD children and adolescents, the fact that they are not available in Portuguese has hampered, among others: understanding of the disease`s impact on daily activities, identification of specific problems, assessment of compliance-related treatment impact and comparison of different treatments.[16]

The purpose of this study was to present the results obtained with the process of translation into and cultural adaptation to Brazilian Portuguese of the Pediatric Quality of Life Inventory Version 3.0 for children and adolescents with advanced-stage renal disease (Peds QL™ 3.0 – ASRD).

METHOD

The process of translation into and linguistic and cultural adaptation to Brazilian Portuguese of the Peds QL™ – ASRD was developed in four stages. This process was approved by the Committee of Research Ethics of the *Hospital das Clínicas* (HC) of the São Paulo University Medical School, as part of the doctorate project of the main researcher. An authorization of the *MAPI Research Trust*, holder of the copyright use of the English version of the original questionnaire, was obtained.

PHASE 1. TRANSLATION OF THE ORIGINAL VERSION

Translation of the original questionnaire, from English to Brazilian Portuguese, was made by two bilingual Brazilian translators who did not work in the health field. The translations were independently made, the translators being only aware of the objective of the questionnaires and their target population. The local committee, composed of a nurse and a pediatric nephrologist, analyzed the two translations and elaborated a single one, which was linguistically and conceptually equivalent.

PHASE 2. BACK-TRANSLATION INTO ENGLISH

The version resulting from phase 1 was back-translated into the original language, by a translator whose mother-tongue was English and who had a good command of Portuguese. The translator, who did not work in the health field and who was informed about the objective of the questionnaires and their target population, did not have access to the original version. At the end of this stage, a second version of the questionnaire was obtained, a report being produced and sent to the copyright holder institution.

PHASE 3. APPLICATION TO A GROUP OF PATIENTS

The Portuguese version of the questionnaire, resulting from phase 1, was applied to a patients` sample. The objectives were to assess whether the version was acceptable and understandable, with simple and appropriate language, and to identify items or instructions leading to misunderstanding on the part of the children, adolescents or caregivers.

PHASE 4. PROOF-READING AND FINALIZATION

The last phase consisted of a discussion of the impressions obtained during the application of the Portuguese version, along with the linguistic and grammar analyses made by a Brazilian expert in Portuguese. This latter professional, also not working in the health field, was informed on the objective of the questionnaires. The final versions were finalized after the end of phase 4.

PEDS QL™ – ASRD VERSION 3.0 – CHILDREN AND ADOLESCENTS` VERSION

This set of questionnaires, developed by James W. Varni *et al.* in English, is an attempt to measure the

QL of ASRD children and adolescents, through a self-assessment performed by the child or adolescent and through a parents` report. Assessments are made with a scale that represents different levels of perception of the problems occurring in the previous month. Peds QL™ 3.0 is composed of questionnaires specific to the 5-7, 8-12 (Appendix 1) and 13-18 years age ranges, with language that is adequate to each developmental level.

Each questionnaire is composed of 34 questions, grouped in 7 items, which encompass health perception in the following areas: "general fatigue", "about my disease", "problems with treatment", "interaction with family and friends", "worry", "perception of the physical looks" and "communication". The questionnaire for the 5-7 years age range is applied with the help of a three-face chart (Appendix 2), whose aim is to express the satisfaction, with the following variations: "never" (being zero), "sometimes" (being two) and "very much" (being four). For the older age ranges, the satisfaction scale ranges from 0 to 4, zero indicating that "it is never a problem", 1 that "it is hardly a problem", 2 that "it is sometimes a problem", 3 that "it is often a problem" and 4 that "it is almost always a problem".

Peds QL™ Version 3.0 – parents` version

The parents` questionnaire has also versions for the 5-7, 8-12 (Appendix 3) and 13-18 years age ranges, each one composed of 34 questions grouped into 7 items, encompassing health perception on the following areas: "general fatigue", "about the renal disease", "problems with the treatment", "interaction with family and friends", "worry", "perception of the physical looks", and "communication".

There is also a questionnaire specific for parents of children aged 2-4 years, which differs from the others by the total number of questions (13 questions), grouped into the following domains: "general fatigue", "about the renal disease", "problems with the treatment" and "worry". This questionnaire has the same satisfaction scale of the questionnaires aimed at the children over the age of 8 years, with the respective 0 to 4 values.

The alternatives are converted into scores, whose values are proportionally distributed and whose total ranges from 0 to 100 points. The items are grouped into different domains which, after the means is obtained, have their final values between 0 and 100 points. Although there is no cutoff point, it is understood that the approximations of the upper summation are considered positive for QL. If more than 50% of the items of each domain are not answered, the module summation will not be computed.[5]

Study population

We included 2-18-year-old children and adolescents (stages 4 or 5 CRD) followed up at the Nephrology Unit of the Child Institute of the University of São Paulo Medical School Hospital. We also included one caregiver for each child. The questionnaires were applied at the Pediatric Nephrology Outpatient Facility, Dialysis Unit and General Ward. The questionnaires for the 5-7-year-old children were applied by an interviewer with experience with pediatric QL questionnaires. Most of the other age-specific questionnaires were self-applied by the patients or parents. The interviewer was present at all applications and, in the end, questioned the interviewees about any difficulty found.

Results

Table 1 presents the demographic profile of the children and adolescents, according to age range, sex and CRD treatment. We invited and included in the study 20 caregivers and 15 children or adolescents, 5 from each age range, according to the questionnaires, as advised by the instruments` author, totaling 35 interviews. The definitive version obtained in phase 4 was used. No patient or caregiver refused to participate in the validation phase. All participants understood and answered the questionnaires, no significant difficulty being identified. Questionnaire application lasted about 5 minutes.

Cultural adaptation

The questions proposed in the Peds QL™ 3.0 questionnaires are specific for ASRD children and adolescents. We sought semantic equivalence (equivalence between the words), idiomatic equivalence (equivalent expressions not found or items which had to be replaced) and experimental equivalence (words and situations adequate to the Brazilian cultural context).[32,33]

Portuguese has a peculiar use of pronouns. The English pronoun your, for example, may be translated as *seu*, keeping gender neutrality or by *sua*, specifying the female gender, according to context. Because of the predominantly low schooling of the interviewees, which could hamper reading and interpretation of the questions, we kept the gender difference, with inclusion of the *seu/sua* pronouns in the questions. The

Table 1 PROFILE OF THE CHILDREN AND ADOLESCENTS INTERVIEWED, ACCORDING TO AGE RANGE, SEX, AND CHRONIC RENAL DISEASE (CRD) TREATMENT

Age range (n = 5) Sex	Distribution (n = 20)	Intermittent peritoneal dialysis	Hemodialysis	Renal transplantation	Conservative treatment
2 to 4		01	0	0	04
Male	02				
Female	03				
5 to 7		01	0	02	02
Male	04				
Female	01				
8 to 12		03	01	0	01
Male	03				
Female	02				
13 to 18		0	02	03	0
Male	03				
Female	02				
Total		05	03	05	07
Male	12				
Female	08				

same happened with he/she and his/her pronouns, which were translated as *ele/ela* and *dele/dela*.

The English questionnaire, called End Stage Renal Disease (ESRD), had its first two translations as *Doença Renal em Estágio Final* and *Doença Renal em Estágio Terminal*. However, we chose to use *Doença Renal em Estágio Avançado* (Advanced Stage Renal Disease), to avoid the potentially negative impression conveyed by the words *final* and *terminal* to the patients and their caregivers.

There was a change in the "*Sobre minha doença renal*" (about my kidney disease) domain of the questionnaires aimed at the parents` report. It was understood that it would be more appropriate to use "*Sobre a doença renal*", once the possessive my refers to the individual with the renal disease, the pediatric patient in this particular instance.

Muscle cramps are frequent in patients with hypokalemia or hypovolemia, clinical conditions found in those on intermittent peritoneal dialysis or hemodialysis. In the 5-7 years questionnaire, the expression *fisgadas nos músculos* was added to the word *cãibras*, in order to facilitate the children`s comprehension, once cramp-related symptoms are not associated with muscle contractures by children at this age range.

The original questionnaire, in English, presents a special professional category known as child life specialist. This professional, an expert on the psychological and educational aspects surrounding childhood growth and development, is not part of the multiprofessional team caring for the Brazilian pediatric population. Therefore, we sought an approximation by referring to the psychologist, a professional who is part of most such teams in Brazil.

Portuguese uses ellipsis, such as the occultation of subjects and verbs, to avoid repetition. However, children at the very early phases of education have difficulty reading and comprehending elaborate sentences. Although the omission of the subject and verb, at the end of the sentence, left it understated that it referred to the initial subject, we chose to keep the sentence complete – and only in the self-applied questionnaires for this age range. Therefore, the question "*É difícil para você beber a quantidade de líquidos que você deveria beber?*" (is it difficult for you to drink the necessary amount of liquids?), for example, was kept grammatically redundant, in order to ease the comprehension of the study population.

ASRD children and adolescents have an altered daily routine, which is characterized by a large intake of medications, dietary restrictions and, in selected cases, due to the underlying disease or dialysis modality, restrictions to the practice of physical activities.[11] Furthermore, prolonged contact with the health team makes patients and family master the technical vocabulary, which contains expressions such as blood pressure (BP), cramps and infection, which has facilitated question comprehension.

Nevertheless, the preoccupation to adequate the language to daily use within the Brazilian cultural context justified the use of expressions such as "*tratamento médico estar funcionando*" (medical treatment is working), *"ficar de fora das atividades"* (stay out of activities), *"pegar infecções"* (catch infections) and "*ser picado(a) por agulhas"* (be pricked by needles). When written, these expressions are closer to what is routinely spoken by the children and caregivers. Their use, therefore, aimed to facilitate self-application by the study population.

DISCUSSION

We reported the results of the process of translation into and cultural adaptation to Brazilian Portuguese of the Peds QL™ 3.0, an instrument aimed at the assessment of QL of ASRD children and adolescents through self-assessment made by the patients and their caregivers.

Translation involves interpretation of words from one language so that they can be expressed in another, whereas linguistic adaptation of a questionnaire involves adaptation to a different culture, with prioritization of clarity, the use of ordinary language and conceptual adequacy, in addition to assessment of its pertinence to the other culture.[32] It is thus important to discuss the equivalences, in order to obtain relevance and pertinence, essential to an easy implementation.

Instruments for assessing QL may be classified as general or specific. General instruments help to compare different population groups, affording wide variation of the different aspects related to the individual`s QL. Specific instruments are used to make inferences about the QL of patients with chronic diseases, as these instruments are sensitive to alterations occurring during the disease process, which makes them an excellent choice for certain groups.[2,6,11]

The importance of instruments for QL assessment lies in the fact that measures oriented by and to the patient may be implemented, and also in the provision of parameters to the teams responsible for the long-term follow-up of these patients. Because they take into account the several aspects involving growth and development, instruments specially developed for the pediatric population tend to perceive the children`s health status according to the different age ranges.[2,11]

The absence of a specific instrument targeting ASRD children and adolescents, validated for Portuguese, has delayed the reflection on the disease implications in this group and hampered the collection of data that could inform appropriate interventions.[2,22,34] The translation of the questionnaire for ASRD patients aimed to adequate the care, both of the group, according to the unit where it is rendered, and of the individual, through data obtained in the interviews.[17]

ASSESSMENT OF QL OF ASRD CHILDHOOD PATIENTS

Interest in QL focuses on the early identification of the impact of chronic diseases, due to last till adulthood, and on the identification of specific problems, such as treatment compliance. Treatment failure and disease-related limitations impair the individual`s physical and mental integrity. CRD children and adolescents are restricted in their ability to partake in fun activities, with consequent impairment of their self-esteem and the need of point interventions to reduce emotional sequelae.[1,13,18,28,35-40]

Inferences about QL in childhood are a challenge for health professionals.[19] Therefore, the use of specific instruments has helped to differentiate the impact produced by the different therapies, stimulating their adequacy to the patient`s lifestyle, with needs and wishes being taken into account. The instruments must thus be simple to answer, easy to assess, and rich in useful information on which to base the interventions, always considering that treatment of chronic diseases frequently goes beyond mere drug therapy. We concluded that the method used in the translation was useful throughout the process of cultural adaptation, resulting in a version that is easily comprehended and applied.[2,15-17,21-23,27]

ACKNOWLEDGEMENTS

We thank Guilherme Arruda e Silva, Sérgio dos Santos Abreu Filho and Joel Kenneth Rast, translators, and Jorge Alves de Lima, reviewer, for their excellent contribution to this study.

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Appendix 1

Children`s report (8 to 12 years)

Fadiga geral

1. Eu me sinto cansado(a).
2. Eu me sinto fisicamente fraco(a), (sem força).
3. Eu me sinto muito cansado(a) para fazer coisas que gosto de fazer.
4. Eu me sinto cansado(a) para passar tempo com os meus amigos.

Sobre minha doença renal

1. Meu rosto fica inchado.
2. Eu me sinto tonto(a).
3. Eu tenho dores de cabeça.
4. Eu tenho sede.
5. Eu tenho cãibras musculares.

Problemas no tratamento

1. É muito difícil me lembrar de tomar meus medicamentos.
2. Eu não gosto de como me sinto após tomar meus medicamentos.
3. É difícil beber a quantidade de líquidos que eu deveria beber.
4. Eu fico irritado(a) quando não posso comer alimentos que quero comer.

Interação com família e amigos

1. É difícil para mim quando outras pessoas não entendem sobre a minha doença.
2. Eu não posso realizar atividades com minha família por causa do meu tratamento.
3. Eu me sinto de fora das atividades com os meus amigos por causa do meu tratamento.

Preocupação

1. Eu me preocupo se meu tratamento médico está funcionando ou não.
2. Eu me preocupo com a necessidade de cirurgia.
3. Eu me preocupo em permanecer doente por um longo tempo.
4. Eu me preocupo que terei que ficar no hospital.
5. Eu me preocupo com minha pressão arterial.
6. Eu me preocupo que ficarei doente se não tomar meus medicamentos.
7. Eu me preocupo com meu peso.
8. Eu me preocupo em pegar infecções.
9. Eu me preocupo em ser picado por agulhas (por exemplo, injeções, exames de sangue, medicamentos intravenosos).
10. Eu me preocupo com os resultados de meus exames de sangue.

Percepção da aparência física

1. Eu não gosto que outras pessoas vejam minhas cicatrizes.
2. Eu não aparento ter a mesma idade que outras crianças da minha idade.
3. Eu me sinto envergonhado(a), pois os medicamentos mudarão minha aparência.

Comunicação

1. É difícil contar aos médicos e enfermeiros como me sinto.
2. É difícil fazer perguntas aos médicos e enfermeiros.
3. É difícil contar para outras pessoas no hospital (por exemplo, psicólogo, nutricionista e assistente social) como me sinto.
4. É difícil explicar minha doença para outras pessoas.
5. É difícil contar aos meus pais como me sinto.

Appendix 2

Quanto este problema significa para você?

Nunca	Às vezes	Muito
☺	😐	☹

Appendix 3

Parents` report about their children (8 to 12 years)

Fadiga geral

1. Se sentir cansado(a).
2. Se sentir fisicamente fraco(a), (sem força).
3. Se sentir muito cansado(a) para fazer coisas que ele(a) gosta de fazer.
4. Se sentir muito cansado(a) para passar algum tempo com os amigos dele(a).

Sobre a doença renal

1. Inchaço no rosto.
2. Se sentir tonto(a).
3. Ficar com dores de cabeça.
4. Ficar com sede.
5. Ter cãibras musculares.

Problemas no tratamento

1. Ter dificuldade para se lembrar de tomar os medicamentos dele(a).
2. Não gostar de como se sente após tomar os medicamentos dele(a).
3. Ter dificuldade de beber a quantidade de líquidos que ele(a) deveria.
4. Ficar nervoso(a) quando não pode comer alimentos que ele(a) gostaria de comer.

Interação com família e amigos

1. Ter dificuldade quando outros pessoas não entendem a doença dele(a).
2. Não ser capaz de realizar atividades com a família devido ao tratamento dele(a).
3. Se sentir de fora das atividades com os amigos por causa do tratamento dele(a)

Preocupação

1. Se preocupa se o tratamento médico dele(a) estão funcionando ou não.
2. Se preocupa com a necessidade de cirurgia.
3. Se preocupa se permanecerá doente por um longo tempo.
4. Se preocupa que precisará permanecer no hospital.
5. Se preocupa com pressão arterial dele(a).
6. Se preocupa que ficará doente se não tomar os medicamentos dele(a).
7. Se preocupa com o peso dele(a).
8. Se preocupa em pegar infecções.
9. Se preocupa em ser picado(a) por agulhas (por exemplo, infecções, exames de sangue, medicações intravenosas).
10. Se preocupa com os resultados dos exames de sangue dele(a).

Percepção da aparência física

1. Não gostar que outras pessoas vejam as cicatrizes dele(a).
2. Não aparentar ter a mesma idade que outras crianças da idade dele(a).
3. Se sentir envergonhado(a), pois os medicamentos mudarão a aparência dele(a).

Comunicação

1. Dificuldade de dizer aos médicos e enfermeiros como ele(a) se sente.
2. Dificuldade de fazer perguntas aos médicos e enfermeiros.
3. Dificuldade em contar para outras pessoas no hospital (por exemplo, psicólogo, nutricionista e assistente social) como ele(a) se sente.
4. Dificuldade ao explicar a doença dele(a) para outras pessoas.
5. Dificuldade de contar aos pais como ele(a) se sente.