Reliability of the Brazilian version of the PedsQL - ESDR questionnaire to evaluate quality of life of children and adolescents

Authors
Marcos Thomazin Lopes[1]
Alexandre Archanjo Ferraro[1]
Vera Hermina Kalika Koch[1]

[1] Universidade de São Paulo.

Submitted on: 08/11/2014.
Approved on: 01/30/2015.

Correspondence to:
Marcos Thomazin Lopes.
Children's Institute, University Hospital, School of Medicine, University of São Paulo.
Av. Enéas de Carvalho Aguiar, nº 647, Cerqueira César, São Paulo, SP.
CEP: 05403-000
E-mail: marcos.lopes@hc.fm.usp.br

DOI: 10.5935/0101-2800.20150026

ABSTRACT

Objective: To evaluate the reliability of the translation and cultural adaptation of the Pediatric Quality of Life Inventory (PedsQL™) - End Stage Renal Disease (ESRD) - version 3.0 - children/adolescents and parents reports in Brazilian children with ESRD. **Methods:** A group of 24 children and adolescents with ESRD, followed at Unidade de Nefrologia Pediátrica do Instituto da Criança - HCFMUSP and 32 primary caregivers were interviewed according to the me methodology proposed by the creator of the original questionnaire. Results: Statistical analysis using Cronbach's alpha resulted in values between 0.39 and 0.89 for all domains in initial statistical analysis. The domains that presented values lower than 0.5 were recalculated by age group, resulting in higher Cronbach´s alpha values demonstrating the influence of the age in the perception of quality of life in ESRD patients. The overall rating of Cronbach´s alpha values resulted in values of 0.81 and 0.71 in patients and PC reports, respectively, demonstrating good internal consistency. **Conclusions:** Ours results show that the Brazilian version of the questionnaires is valid, reliable and useful for measure HRQoL of children and adolescents ESRD, according to patients and PC reports.

Keywords: child; quality of life; questionnaires; renal insufficiency.

INTRODUCTION

The incidence and prevalence of end-stage renal disease (ESRD) in children have increased. In 2008, the median global incidence of renal replacement therapy (RRT) in children and adolescents aged between zero and 19 years was four per million and 18 per million age-related population respectively, while prevalence ranged from 18 to 100 per million age-related population. According to the 2013 Census of the Brazilian Society of Nephrology, an estimated 100,000 patients were on dialysis nationwide, 0.4% of whom aged between one and 12 years.[1,2]

ESRD is characterized by irreversible loss of renal function and decline in glomerular filtration rate to levels below 29 ml/min/1.73 m^2, followed by impairment of regulatory, excretory and endocrine function. The etiology of pediatric ESRD presents unique characteristics when compared to the disease in adults. The disease in children is based on congenital causes, with two thirds of the cases stemming from urinary system anomalies or inherited kidney disease. Hypertension, obesity, and low birth weight also rank among potential risk factors for the development of renal disease.[1-6]

Early diagnosis and adequate treatment are of paramount importance in delaying the progress of disease and ensuring good-quality patient survival. However, children with ESRD may experience intense psychological distress during the course of the disease, which negatively affects their development and favors the onset of emotional instability, high levels of anxiety, low self-esteem, behavioral disorders, and deleterious impacts on their quality of life (QoL) and on that of their primary caregivers (PC).[7-15]

In healthcare, QoL gained additional relevance when it was incorporated in the assessment of treatment outcomes, which led to the emergence of the idea of health-related quality of life (HRQoL). According to Erling, HRQoL includes the patients' perceptions of health and treatment along with the assessment of the quality, effectiveness and efficiency of the care provided based on the observed impact.[6,16-32]

In pediatric patients, HRQoL considers the difference between the expectations of patients and their families in regards to treatment - which may vary depending on individual expectations and past experiences with healthcare and illness. HRQoL has gained significant ground in supporting healthcare workers involved in the management of pediatric patients with different levels of impairment.[4,33-38]

The scales and instruments used to assess HRQoL must encompass multiple dimensions in order to capture an individual's perceptions over aspects concerned with QoL. Ideally, these scales should match the respondent's ability to understand and answer the questions in them, while providing useful information that may be reutilized in future interventions tailored to the specific needs of the patients as per the captured perceptions. The purpose of these scales, therefore, is to enable patients to share their impressions on the disease afflicting them.[17,20,22,30]

The Pediatric Quality of Life Inventory (Peds QL)™ 3.0 End-Stage Renal Disease (ESRD) module - Child/Adolescent Self-Report and Parent Proxy-Report was developed by Varni *et al*. to assess the HRQoL of patients with ESRD stages 4 and 5 as perceived by the patients themselves and their parents. This instrument looks into satisfaction with the treatment and allows insight into the patients' needs as per their own and their primary caregivers' views. In order for the Brazilian Portuguese version of the scale to be as effective and reliable as its original counterpart in English, it must undergo a thorough process of validation, which includes translation and cultural adaptation of the scale to the local reality.[18]

This paper aims to present the outcomes of the calculations carried out as part of the validation process of the Brazilian Portuguese version of the Peds QL™ 3.0 ESRD Module used to assess the QoL of children and adolescents with ESRD.

MATERIALS AND METHOD

This study is part of the ongoing process of translating and linguistically adapting the Peds QL™ 3.0 scale into Brazilian Portuguese for use in the assessment of HRQoL of Brazilian children and adolescents with ESRD. The main project was approved by the Research Ethics Committee of the University Hospital (HC) of the School of Medicine of the University of São Paulo (USP) and granted permit 0082/10. The MAPI Research Trust - the institution responsible for the original scale and all its versions - granted the study permission to carry out the translation, cultural adaptation, and validation of the scale.

The study enrolled children and adolescents aged between two and 18 years with ESRD stages 4 and 5 followed up in the Nephrology Unit of the Children's Institute at HCFMUSP and their respective primary caregivers.

The questionnaires were answered while patients and parents were at the Pediatric Nephrology Clinic or at the Dialysis Unit. Primary caregivers were first explained the purposes of the study and invited to join in. Those willing to participate were asked to give informed consent and were then interviewed for patient demographics and clinical data and PC demographics. The questionnaires were applied during outpatient visits or dialysis sessions. A researcher was present during most of the sessions to read the questions in the scale to the patients or to aid participants who answered the questions on their own and address comprehension issues.

The Peds QL™ 3.0 contains specific questionnaires for individuals in the 5-7, 8-12, and 13-18 year-old age groups, with 34 questions grouped into seven domains (General Fatigue, About My Kidney Disease, Treatment Problems, Family & Peer Interaction, Worry, Perceived Physical Appearance, and Communication) (Appendix 1).[18] The parent proxy-report questionnaires are structured equally, but there is a specific set of 13 questions for children aged between two and four years grouped into four domains (General Fatigue, About My Kidney Disease, Treatment Problems, and Worry) (Appendix 2).[18]

The answers to each question are numbered from zero to four and converted into a score in which 0 = 100; 1 = 75; 2 = 50; 3 = 25; and 4 = 0. Domains with more than 50% of the questions left unanswered are not considered. While there is no cutoff point, scores close to 100 are deemed positive for QoL.[39]

Statistical analysis

Sample size was calculated using software program StatsToDo and Cronbach's Alpha. The mean score in each domain was calculated by dividing the sum of the scores by the number of given answers. Cronbach's Alpha was also used in the separate comparison of mean domain scores and total scores.

Results

Table 1 shows the demographic and clinical profiles of the interviewed patients (n = 24) in terms of age, gender, and treatment mode, in addition to relevant primary caregiver information (n = 32).

The final version of the translated scale was used in the interviews.[18] None of the invited primary caregivers or patients refused to join the validation of the scale. All participants were able to comprehend and answer the questions in the scale. It took participants approximately five minutes to answer the questionnaire. In every domain, more than 50% of the questions were answered.

Table 2 shows the mean scores and the Cronbach's Alpha of the seven domains separately, as calculated from the reports, and the scores pertaining to all domains in the child/adolescent self-reports and parent proxy-reports for each set of questionnaires.

Once the initial calculations yielded a Cronbach's Alpha under 0.50 for domains *About My Kidney Disease* and *Treatment Problems* in the child/adolescent self-reports and parent proxy-reports, the patients were regrouped into three age ranges (0-7; 8-12; 13-18 years) and their scores recalculated (Table 3).

Discussion

The scales currently used to assess the QoL of Brazilian pediatric patients were entirely developed abroad, particularly in English-speaking countries. Their validity and reliability must be placed under scrutiny, in order to ensure they are internally consistent and able to soundly indicate the correlations between studied items and overall results as obtained from a social context different from the one for which the scales were originally intended.[17-19,30]

The translation and ensuing cultural and linguistic validation of the Brazilian Portuguese Peds QL™ 3.0 scale used to assess the QoL of

Table 1 Distribution of demographic and clinical profiles of interviewed children and adolescents (n = 24), according to age range, gender, and treatment, and relevant interviewed PC information (n = 32) such as gender, age range, and level of education

Description	Frequência (%)
Patient gender	
Female	14
Male	18
Total	32 (100)
Age range	
2-4 years	08
5-7 years	03
8-12 years	05
13-18 years	16
Total	32 (100)
Treatment mode	
Drug therapy	02
Hemodialysis	24
Peritoneal dialysis	02
Transplantation	04
Total	32 (100)
Interviewed caregiver	
Father	02
Mother	29
Others	01
Total	32 (100)
Interviewed caregiver age	
30 years and younger	07
30-45 years	17
45 years or older	08
Total	32 (100)
PC level of education	
Illiterate	01
Incomplete Elementary Education	09
Complete Elementary Education	02
Incomplete Middle School	03
Complete Middle School	10
Incomplete Higher Education	01
Complete Higher Education	06
Total	32 (100)

children and adolescents with ESRD included steps such as translation of the original scale into Brazilian Portuguese, translation of the Brazilian Portuguese version back into English, application of the scale to a group of patients, proof reading, and final review.[18]

Given that the scale is used specifically to study individuals with ESRD at different stages of growth and development, statistical analysis was carried out in order to assess the sensitiveness of the scale when applied to Brazilian patients. Cronbach's Alpha was chosen to estimate the reliability of the scale for its track record with other similar scales and its use in the analysis of respondent answer profiles.

Despite the lack of agreement around a reference value for Cronbach's Alpha, some authors have considered 0.50 as appropriate, which was the case in almost every item analyzed in this study and in the global assessment of the questionnaires. These results have suggested the original scale is accurate and confirmed the use of the translated and adapted version.

Final considerations

The QoL of pediatric patients with ESRD must be assessed throughout the delivery of treatment. The availability of specific, regionally validated scales enhances patient QoL monitoring and allows for outcome comparisons between centers within the same region or from different areas of the globe, in addition to guiding the adoption of therapeutic measures.

This paper presented the validation process of a QoL assessment scale used with children and adolescents with ESRD, which proved valid, reliable, and useful in our setting. It is our hope that the pediatric nephrology community incorporates the scale into routine practice and that the expected refinement of the care provided to pediatric patients with ESRD materializes.

Acknowledgements

The authors would like to thank Prof. James W. Varni, from Texas A&M University, and the MAPI-Institute for allowing the scale to be translated and validated for our language/culture, and for aiding the authors in various stages of the process.

Table 2 Distribution of mean values and cronbach's alpha for each domain and Peds ql™ 3.0 esrd module - child self-reports and parent proxy-reports

Domain	Child self-reports (n = 24)		Parent proxy-reports (n = 32)	
	Mean	Alpha	Mean	Alpha
General fatigue	73.35	0.55	90.23	0.81
About my kidney disease	59.55	0.39	74.78	0.50
Treatment problems	61.28	0.56	78.27	0.42
Family & peer interaction	56.25	0.52	71.01	0.63
Worry	48.76	0.77	72.31	0.89
Perceived physical appearance	62.78	0.63	79.28	0.63
Communication	74.93	0.62	77.45	0.84
Combined domains	62.22	0.81	72.57	0.71

Table 3 Distribution of cronbach's alpha on domains about my kidney disease and treatment problems in the peds qltm 3.0 esrd module - child self-reports and parent proxy-reports according to age range

Domain	Age group distribution		
	7 years and younger (n = 11)	8-12 years (n = 5)	13-18 years (n = 16)
Child self-reports About My Kidney Disease	--	0.47	0.65
Parent proxy-reports Treatment Problems	0.54	0.77	0.64

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APPENDIX 1

CHILD REPORT (8 TO 12 YEARS)

GENERAL FATIGUE

1. I feel tired
2. I feel physically weak (not strong)
3. I feel too tired to do things that I like to do
4. I feel too tired to spend time with my friends

ABOUT MY KIDNEY DISEASE

1. I get swelling in my face
2. I feel dizzy
3. I get headaches
4. I get thirsty
5. I get muscle cramps

TREATMENT PROBLEMS

1. It is hard for me to remember to take my medicines
2. I don't like how I feel after I take my medications
3. It is hard for me to drink the amount of fluid I'm supposed to
4. I get upset when I cannot eat foods that I want to eat

FAMILY AND PEER INTERACTION

1. It is difficult for me when other people don't understand about my illness
2. I can't do things with my family because of my treatment
3. I feel left out of activities with my friends because of my treatment

WORRY

1. I worry about whether or not my medical treatments are working
2. I worry about having surgery
3. I worry that I will be sick for a long time
4. I worry that I will have to stay in the hospital
5. I worry about my blood pressure
6. I worry that I will get sick if I don't take my medicines
7. I worry about my weight
8. I worry about getting infections
9. I worry about having needle sticks (i.e., injections, blood tests, IVs)
10. I worry about the results of my blood tests

PERCEIVED PHYSICAL APPEARANCE

1. I don't like other people to see my scars
2. I don't look as old as other kids my age
3. I am embarrassed that my medicines will change the way I look

COMMUNICATION

1. It is hard for me to tell the doctors and nurses how I feel
2. It is hard for me to ask the doctors and nurses questions
3. It is hard for me to tell other people at the hospital (i.e., child life, dietician, social worker) how I feel
4. It is hard for me to explain my illness to other people
5. It is hard for me to tell my parents how I feel

APPENDIX 2

PARENT REPORT FOR CHILDREN (AGES 8 TO 12)

GENERAL FATIGUE

1. Feeling tired
2. Feeling physically weak (not strong)
3. Feeling too tired to do things that he/she likes to do
4. Feeling too tired to spend time with his/her friends

ABOUT MY KIDNEY DISEASE

1. Swelling in his/her face
2. Feeling dizzy
3. Getting headaches
4. Getting thirsty
5. Getting muscle cramps

TREATMENT PROBLEMS

1. Difficulty remembering to take his/her medicines
2. Not liking how he/she feels after taking his/her medications
3. Difficulty drinking the amount of fluid he/she is supposed to
4. Getting upset when he/she cannot eat foods that he/she wants to eat

FAMILY AND PEER INTERACTION

1. Difficulty when other people don't understand about his/her illness
2. Not being able to do things with his/her family because of his/her treatment
3. Feeling left out of activities with his/her friends because of his/her treatment

WORRY

1. Worrying about whether or not his/her medical treatments are working
2. Worrying about having surgery
3. Worrying that he/she will be sick for a long time
4. Worrying that he/she will have to stay in the hospital
5. Worrying about his/her blood pressure
6. Worrying that he/she will get sick if he/she doesn't take his/her medicines
7. Worrying about his/her weight
8. Worrying about getting infections
9. Worrying about having needle sticks (i.e., injections, blood tests, IVs)
10. Worrying about the results of his/her blood tests

PERCEIVED PHYSICAL APPEARANCE

1. Not liking other people to see his/her scars
2. Not looking as old as other kids his/her age
3. Being embarrassed that his/her medicines will change the way he/she looks

COMMUNICATION

1. Difficulty telling the doctors and nurses how he/she feels
2. Difficulty asking the doctors and nurses questions
3. Difficulty telling other people at the hospital (i.e., child life, dietician, social worker) how he/she feels
4. Difficulty explaining his/her illness to other people
5. Difficulty telling his/her parents how he/she feels