

Cultural adaptation and initial psychometric properties of the DISABKIDS® – Cystic Fibrosis Module – Brazilian version

ADAPTAÇÃO CULTURAL E PROPRIEDADES PSICOMÉTRICAS INICIAIS DO INSTRUMENTO DISABKIDS® – CYSTIC FIBROSIS MODULE – VERSÃO BRASILEIRA

ADAPTACIÓN CULTURAL Y PROPIEDADES PSICOMÉTRICAS INICIALES DEL INSTRUMENTO DISABKIDS® – CYSTIC FIBROSIS MODULE – VERSIÓN BRASILEÑA

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ABSTRACT

This study aimed to perform the cultural adaptation and describe the initial psychometric properties of the DISABKIDS® – Cystic Fibrosis Module instrument to measure health-related quality of life for children and adolescents and their parents/caregivers. Methodological study of sequential development, including 126 participants in four Brazilian states. Involved translation and back translation of items, semantic and conceptual equivalence, face validity and description of the initial psychometric properties related to the construct and reliability. For semantic equivalence of the adapted version, there were adjustments in the phrasing of an item. The instrument showed satisfactory internal consistency with Cronbach's alpha values between 0.70 and 0.85, convergent validity with correlation values above 0.40 in 85% of the items and divergent validity with scale fit higher than 75%. The Brazilian version of DISABKIDS® – CFM will certainly constitute a valid and reliable instrument for measuring the quality of life of Brazilian children and adolescents with cystic fibrosis.

DESCRIPTORS

Child
Adolescent
Cystic fibrosis
Quality of life
Validation studies

RESUMO

Este estudo objetivou adaptar culturalmente e descrever as propriedades psicométricas iniciais do instrumento de mensuração de qualidade de vida relacionada à saúde de DISABKIDS® – *Cystic Fibrosis Module* para crianças e adolescentes e seus pais/cuidadores. Estudo metodológico de desenvolvimento sequencial, incluindo 126 participantes em quatro estados brasileiros. Envolveu tradução e retrotradução dos itens, equivalência conceitual e semântica, validade de face e descrição das propriedades psicométricas iniciais relacionadas ao construto e fidedignidade. Para equivalência semântica da versão adaptada houve ajustes na redação de um item. O instrumento apresentou consistência interna satisfatória com valores de alfa de Cronbach entre 0,70 e 0,85, validade convergente com valores de correlação acima 0,40 em 85% dos itens e validade divergente com valores de ajuste superiores a 75%. A versão brasileira do DISABKIDS® – CFM certamente se constituirá em um instrumento válido e confiável para a mensuração da qualidade de vida de crianças e adolescentes brasileiros com fibrose cística.

DESCRIPTORES

Criança
Adolescente
Fibrose cística
Qualidade de vida
Estudos de validação

RESUMEN

Este estudio tuvo como objetivo adaptar culturalmente y describir las propiedades psicométricas iniciales del instrumento de medida de la calidad de vida relacionada a la salud, DISABKIDS® – *Cystic Fibrosis Module* para niños/adolescentes y sus padres/cuidadores. Estudio metodológico de desarrollo secuencial, incluyendo 126 participantes en cuatro estados brasileños. Envolvió la traducción y retro-traducción de los ítems, la equivalencia conceptual y semántica, la validez externa y la descripción de las propiedades psicométricas iniciales con relación al constructo y la confiabilidad. Para la equivalencia semántica de la versión adaptada hubo ajustes en la redacción de un ítem. El instrumento presentó consistencia interna satisfactoria con valores de alfa de Cronbach entre 0,70 y 0,85, validez convergente con valores de correlación superiores a 0,40 en 85% de los ítems y validez divergente con valores de ajuste superiores a 75%. La versión brasileña del DISABKIDS® – CFM ciertamente será un instrumento válido y confiable para medir la Calidad de Vida de niños y adolescentes con fibrosis quística.

DESCRIPTORES

Niño
Adolescente
Fibrosis quística
Calidad de vida
Estudios de validación

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INTRODUCTION

Cystic Fibrosis (CF) is a chronic condition that has an autosomal recessive pattern of inheritance, which presents clinical forms of different severity, with the most common features of their carriers, chronic lung disease, pancreatic insufficiency and high content of sodium chloride in sweat. Due to the many clinical manifestations, its treatment is complex and may lead to adverse situations related to a large number of medications and interventions⁽¹⁾. Beyond the physical aspects, the social dimensions can also be affected depending on, especially, the age at which the first manifestations occurred⁽²⁾. The CF still present stigmatizing characteristics such as clubbing of the fingers and barrel chest⁽²⁾.

The use of instruments for measuring quality of life (QOL) and health-related quality of life (HRQOL) have been identified as an important tool to evaluate patients with CF in a progressively way and contribute to clinical protocols and therapeutic guidelines, considering emotional and social aspects, beyond the expectations of the patient in relation to their health⁽³⁻⁵⁾.

In children and adolescents this assessment is very important since chronic condition alters their life routine, imposing new priorities at the expense of play-time plus the need to adapt to new limitations, such as physical, nutritional and social limitations⁽⁶⁾. Some studies have shown that hospitalized children and adolescents had lower HRQOL scores for emotional, social and body image dimensions⁽⁷⁾ and children may have lower HRQOL than adolescents because they do not understand their condition and treatment⁽⁶⁾, which makes them feel as something imposed on their life.

In order to contribute to better monitoring of children and adolescents with CF, this sequential approach study⁽⁸⁾ aims to describe the process of cultural adaptation and initial psychometric properties of the DISABKIDS® - Cystic Fibrosis Module (DISABKIDS® - CFM). This instrument is part of the European project DISABKIDS®, kids with disabilities, who works in the development of instruments to measure HRQOL of children and adolescents with chronic conditions. It includes generic modules called DISABKIDS Chronic Generic Module® (DCGM), long-form, DCGM®-37 and short-form, DCGM®-12 and specific modules for arthritis, asthma, atopic dermatitis, diabetes mellitus, epilepsy, cerebral palsy, and the module for cystic fibrosis. In Brazil, the DCGM®-37 and the specific module for atopic dermatitis are also in the process of validation⁽⁹⁻¹¹⁾, besides these, three new modules are in the process of development for children and adolescents with hearing impairment⁽¹²⁾, kidney disease⁽¹³⁾ and acquired immunodeficiency syndrome-AIDS⁽¹⁴⁾.

METHOD

Methodological research with cross-sectional design and sequential approach⁽⁸⁾. The process of cultural adaptation and validation involved the translation and back translation of the items from the original version in English into Portuguese of Brazil, conceptual and semantic equivalence, face validity of the instrument and description of the initial psychometric properties related to construct validity, reliability, existence of floor and ceiling effects and agreement between the responses of children and adolescents and their parents or caregivers.

The population consisted of Brazilian children and adolescents with CF, aged between eight and 17 completed years, and their parents or caregivers. We considered as caregiver the one living together with the child or adolescent. The following inclusion criteria were considered: have cognitive condition consistent with their age and, considering children and adolescents who were not hospitalized. The cognitive status was assessed according to medical records, reports from physicians, parents or caregivers (regarding children or adolescents) and observation of the researcher.

The non-probabilistic sample comprised 126 participants (63 children and adolescents and their respective parents or caregivers), of which 24 (12 children and adolescents and their respective parents or caregivers) participated exclusively of the semantic validation stage and the remaining were part of first stage of the instrument application. Data collection was conducted in reference centers for CF, one in each of these states: Sao Paulo, Minas Gerais and

Parana, and two in the Federal District. Although this is a non-probabilistic sample, we tried to maintain homogeneity in relation to age and gender.

The project was approved by the Research Ethics Committee of the Clinics Hospital, Faculty of Medicine of Ribeirao Preto, University of Sao Paulo, Brazil (HCRP No. 6424/2008). All parents or caregivers signed, along with the researcher, two copies of the Consent Form, and children and adolescents agreed with their participation.

Instrument used

The DISABKIDS®-CFM has a self-version for children and adolescents aged between eight and 17 completed years, and a proxy version with parallel items for parents or caregivers. It is a self-report instrument, short, with ten items whose scores are easily computed. The dimensions evaluated are called impact and treatment. The first, with four items, describes the feeling of tiredness and exhaustion. The second, with six items, refers to the emotional impact of performing the treatment. The answer options are

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given on a five-point Likert scale graded as: never, seldom, quite often, often and always. For each dimension a mean standardized score is obtained. This score ranges from 0% to 100%, 0% being associated with a greater negative impact of the condition on HRQOL and 100% associated with less negative impact.

In order for us to use this instrument and all other modules of the DISABKIDS® in Brazil, the European Group authorized and monitored the whole process of cultural adaptation and validation of their instruments⁽⁹⁻¹⁵⁾.

Cultural adaptation of DISABKIDS®-CFM

In order to perform the cultural adaptation of the instrument, initially we performed the translation and back translation model proposed by the DISABKIDS® group, similar to the method of other groups⁽¹⁶⁻¹⁷⁾. Therefore, the items were translated from the original language (English) into Portuguese by two people with knowledge of the language and mastery of the content studied. The versions were reviewed by the research group involved and a consensus version was drafted. This version was back translated into the original language of the instrument by a bilingual person who did not know the content or the thematic and then compared to the original by the DISABKIDS® project coordinator in Europe. This process required approximately two months to be completed.

Completed this step, we performed between the months of October and December 2008, the semantic, conceptual and face validation of the instrument with the assistance of two specific instruments provided by DISABKIDS® group⁽¹⁸⁾. The first, regards face validity and addresses the general impressions of the instrument, difficulty in answering it and if the items are important for chronic condition. And the specific instrument of semantic validation contains the items of the DISABKIDS®-CFM and questions about the relevance of each item, difficult to understand the items and response categories, with the possibility of reconstruction of the items and how they could be redesigned.

The number of participants at this step was defined according to the method DISABKIDS®, validated in six European countries, as well as in Brazil⁽⁹⁻¹²⁻¹⁹⁾. We organized four groups considering two age groups of children and adolescents participants, 8-12 years and 13-17 years complete. Among the ten items of the DISABKIDS®-CFM instrument, we formed two subsets: subset A, consisting of items 1-5 and subset B consisting of items 6-10. For each of the four groups we considered three children or adolescents and their respective parents and caregivers, totaling 24 participants at this stage.

All participants initially responded to DISABKIDS®-CFM and sequentially filled the general impressions instrument. Subsequently, the participants in each formed subgroup responded to specific instrument questions, relating to the items of their subgroup.

The remaining 102 participants responded to the adapted final version and their responses were used to obtain the initial psychometric properties of the instrument. We decided to adopt a minimum sample of 50 individuals⁽²⁰⁾, homogenous divided by gender and age group (eight to 12 and 13 to 17 years complete), according to the method DISABKIDS®⁽¹⁸⁻¹⁹⁾.

Data analysis

The results of the conceptual equivalence, semantic and face stage were summarized and described according to the calculations of percentages of responses of each item on the relevance, difficulty in understanding the items and the response options. We considered a minimum acceptance percentage of 80% of valid responses for semantic validity of each item and overall impression of the instrument.

Data collection for obtaining the first instrument's psychometric properties occurred between the months of January to October 2009.

We performed the description of the participants distribution according to the instrument responses, aiming to obtain the median, minimum, maximum, mean and standard deviation. Floor and ceiling effects were considered present if more than 15% of participants chose the lowest or highest possible score of the instrument, respectively⁽²⁰⁾.

Reliability was assessed by internal consistency determined by Cronbach's alpha coefficient, the items should be highly correlated with each other within their dimension, since the attribute evaluated theoretically is the same. Its value can vary between zero and one and alpha values above 0.70 and up to 0.95⁽²⁰⁾ are considered acceptable.

The construct validity of the instrument was accessed through convergent and divergent validity according to multitrait-multimethod (MTMM) analysis, which examines the linear correlations between items and dimensions, exploring the relationships between items and dimensions of the instrument⁽¹⁶⁾, using the Multitrait Analysis Program (MAP). In initial validation studies the convergent validity is satisfied if the correlation between an item and dimension to which it belongs is higher than 0.30 and for final studies higher than 0.40⁽¹⁶⁾.

For divergent validity, the MAP program checks the number of times in which the linear correlation between an item and the dimension to which it belongs is greater than or statistically greater the linear correlation between it and the dimension to which it does not belong, providing fit indices of item with its dimension, and the closer to 100% this is the better the divergent validity⁽¹⁶⁾.

The agreement between self and proxy versions was analyzed by using the Intraclass Correlation Coefficient (ICC). The values classification are: below 0.40, weak; between 0.41 and 0.60, moderate; between 0.61 and 0.80, good or substantial; and above 0.81 almost perfect or very good⁽²¹⁾.

The description and analysis of the data was performed using the program Statistical Package for Social Sciences, SPSS®, version 19.0 (License 10101111255, 14/09/2011), with double entry technique so typographical errors of the instruments were minimized.

The level of significance used was 5% ($\alpha=0.05$).

RESULTS

Processes of translation and back translation

After the specific procedures, a back-translated version was sent to the DISABKIDS® project coordinator in Europe, who analyzed and approved it, ensuring their conceptual equivalence. The main orientation was to observe both children and adolescents and their parents or caregivers were aware of what would be *enzymes* (fifth item on both instruments) and whether they understood that *do physiotherapy* (eighth item of both instruments) was related to respiratory physiotherapy.

It is important to note that some expressions and verbs are common to many modules of the DISABKIDS® group, and for the cultural adaptation of the first module⁽⁹⁾ was performed a list of terms with their respective translations in order that the group maintained a standard in the moment of cultural adaptation.

Semantic Validation

The 12 children and adolescents and their respective parents or caregivers completed the instrument separately and alone. There was only one exception, where one of the mothers was illiterate. Children in group 8-12 years had an average age of 10.8 years (SD=1.2 years) and adolescents (group 13-17 completed years), 15 years (SD=1.9 years). As parents or caregivers, the majority of respondents were mothers (83.3%).

Regarding the general impressions instrument about DISABKIDS®-CFM, all participants considered the instrument between great and good. Out of 12 children and adolescents participating in this stage, eight considered items easy to understand. From the group of parents or caregivers, nine of them had the same opinion. All children and adolescents and their parents or caregivers responded they have *none* or *some difficulties* to respond to the instrument, No participant chose the option *a lot of difficulties*. Regarding the relevance of the instrument, ten children and adolescents and eight parents or caregivers have found it very important.

The specific instrument of semantic validation was completed by all participants. The items were considered relevant by at least four of the six children and adolescents who assessed each subset of items. The same result was found between the responses of parents or caregivers. All items were understood without difficulty, with approval of at least five of the six children and adolescents who responded to each subset. Between parents and caregivers of

the twelve participants, only three reported having difficulty on some item, two of them mentioned the ninth item of the instrument (*Have you ever felt that your treatment takes up too much of your free time?*).

The second part, in which the participant was offered the possibility of reconstruction of the item, none of the participants did, although all children and ten parents or caregivers have written how they understood each item.

There was understanding of all items, the way they were formulated, with the exception of the first *Do you get exhausted when you do sports?*, version self and *Does your child get exhausted when he/she does sports?* proxy version. Some responses suggested that both children or adolescents as their parents or caregivers did not understand the word *exhausted*, interpreting it as feeling angry, feeling sick or considering it as a synonymous to the word *tired*.

The suggestion among the responses of those who understood the item was the adoption of the expression *too tired*, proposal that seemed appropriate since most people, healthy or not, get tired to exercise, and the term *too* denotes a tiredness beyond normal and the word *tired* is widely used in daily life.

After modification of the first item, semantic equivalence was reached and the instrument, now culturally adapted was applied to obtain its preliminary psychometric results.

Descriptive statistics of the instrument and first psychometric properties

This step involved 51 children and adolescents and their parents or caregivers, 14 girls and 17 boys from eight to 12 years and 10 boys and girls of 13-18 years. Two families refused to participate in the project and a child did not meet the inclusion criteria due to cognitive problems. The participants demanded an average of 15 minutes to respond to the instrument.

The score calculation was performed using syntax designed for the instrument and made available by the group DISABKIDS®. To be valid, the impact dimension, with four items should be answered in full and the treatment dimension should have at least five items from a total of six. Thus, we obtained as loss, the impact dimension of a parent (2.0%) and a treatment dimension of a child (2.0%).

There was a ceiling effect in impact dimension of self-version, with a value of 27.5%, and the floor effect in the impact dimension on proxy version, with a value of 18%.

The values found for the Cronbach's alpha coefficient was substantial, being within the range of acceptable values between 0.70 and 0.95. The impact dimension presented values of 0.72 and 0.85 for self and proxy version, respectively, and in the treatment dimension the Cronbach's alpha coefficient was 0.73 and 0.83 for self and proxy version, respectively.

There was satisfactory convergent validity for the self-version with values for Pearson's linear correlation coefficient between an item and the dimension to which belongs above 0.40 in 85% of cases, contemplating the final study results⁽¹⁶⁾, as shown in Table 1.

For the divergent validity, the results of both versions, self and proxy were very satisfactory since only the impact dimension of the self-version presented scale fit indices other than 100%, with a result of 75%, which indicates divergent validity of the instrument (Table 1).

Table 1 – Values of Pearson's linear correlation coefficient between items and each dimension, obtained by analyzing MTMM, for the pilot step of validation DISABKIDS®-CFM, for children and adolescents and their parents or caregivers – Ribeirão Preto, SP, Brazil, 2009.

Children and adolescents		Dimension	
Item	Impact	Treatment	
Do you get exhausted when you do sports?	0.55	0.37	
Do you feel tired during the day?	0.59	0.16	
Do you get out of breath?	0.55	0.20	
Do you need to rest more than others?	0.34	0.42	
Does it bother you that you must take your enzymes before every meal?	0.33	0.34	
Does it bother you that you have to eat a special diet to keep you healthy?	0.20	0.34	
Does it bother you that you have to spend a lot of time having treatment?	0.35	0.66	
Are you bothered because you have to do physiotherapy everyday?	0.33	0.66	
Have you felt that your treatment takes up too much of your free time?	0.23	0.63	
Do you feel bothered that you have to stop playing or doing things for treatment?	0.21	0.53	
Adjust	75%	100%	
Parents and caregivers		Dimension	
Item	Impact	Treatment	
1	0.66	0.44	
2	0.84	0.42	
3	0.81	0.36	
4	0.58	0.38	
5	0.45	0.51	
6	0.38	0.45	
7	0.47	0.78	
8	0.09	0.65	
9	0.41	0.67	
10	0.35	0.65	
Adjust	100%	100%	

* Items in the proxy version are parallel to self-version being phrased so as to allow parents or caregivers can respond the items thinking about him/her child or adolescent. Ex: item 1) Does your child get exhausted when he/she do sports?

The agreement between self and proxy responses showed to be substantial⁽²¹⁾ for both the impact and treatment dimension, both with a value of 0.65.

DISCUSSION

The process of cultural adaptation of DISABKIDS®-CFM resulted in the development of a version equivalent to the original and easy to understand for the participants of this study. The Brazilian version is the first to be made available, there is no other instrument versions for different countries⁽¹⁹⁾.

The semantic validation is essential to the reliability and instrument validity. Its purpose is to know how participants understand, accept and consider relevant items of the instrument⁽⁸⁾.

Regarding the recommendation to note whether the participants were aware of what would be *enzymes* and whether they understood that *do physiotherapy* was related to respiratory physiotherapy, we observed by completing the specific instrument of semantic validation, both parents or caregivers such as children and adolescents understand the meaning of words and the two sentences were part of the participants daily lives and these often mentioned until the time that should take the medicine (enzyme) or perform their breathing exercises.

The group that pointed out having a better understanding of the instrument purpose was the adolescents group. They perceived that the intention of the instrument was to contribute to improve aspects of their treatment and activities of daily living. The authors believe that the participation of an illiterate mother at this stage of the research did not impair the process of cultural adaptation, being positive to see the understanding of lower social class (ability). However, being a self-administered instrument and due to the reality of our country, in the future we will need to discuss how the participation of this population may be included, without harming the patient follow-up.

Obtaining the initial psychometric properties allowed a first analysis of the validity and reliability of the adapted version of DISABKIDS®-CFM.

The results identified impact dimension show that effect floor and ceiling should be reassessed in field study, expanding the sample studied. Note that the fourth item of both versions, can cause the presented effect, since studies indicate that participants with some problem or limitation of health can present a sense of negation⁽²²⁾ and on the other hand parents of children and adolescents with some limitation tend to underestimate their health or even weaken it⁽²³⁻²⁴⁾. Yet Abbott et al.⁽⁵⁾ indicate that CF patients tend to have a ceiling effect and caution should be taken so that it does not limit the responsiveness of the instrument, since it changes over time cannot be assigned to the interventions but the presence of this effect.

The internal consistency values found are important since they indicate that each item explains the dimension to which it belongs to and measures the same latent trait besides the fact it does not contain redundant items, identified by the absence of α values greater than 0.95⁽²⁰⁾.

The instrument present construct validity demonstrated by MTMM analysis in which the items of both versions have a linear correlation in most times higher than 0.40 with the dimension which it belongs (convergent validity) and the percentage of items significantly higher with their respective dimensions than with linear correlation with each other is greater than 75% (divergent validity).

The substantial agreement among parents or caregivers and children and adolescents is very important, since after validated and in the impossibility of the usage of the self version, either for physical, clinical or psychological reasons of the participants, the proxy instrument may be used⁽²⁴⁾.

Data collection in several referral centers in different regions of the country gives reliability to the values obtained on the use of the same instrument throughout the country.

CONCLUSION

The results show that the DISABKIDS®-CFM may constitute a valid and reliable instrument to measure HRQOL and it can be inserted into the monitoring routine of Brazilian children and adolescents with CF. Thus, continuity will be given to the validation process DISABKIDS®-CFM, we are now in the step of field testing to verify its final psychometric properties.

In spite of the difficulties of the study, its limitation is the fact that the sample was selected for convenience, as children and adolescents attended to treatment centers, however, as shown, homogeneity remained in age and gender of the participants.

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