

Translation and cultural adaptation of the Brazilian version of DISABKIDS®* Atopic Dermatitis Module (ADM)**

TRADUÇÃO E ADAPTAÇÃO CULTURAL PARA O BRASIL DO *DISABKIDS®* ATOPIC DERMATITIS MODULE (ADM)

TRADUCCIÓN Y ADAPTACIÓN CULTURAL PARA BRASIL DEL *DISABKIDS®* ATOPIC DERMATITIS MODULE (ADM)

Keila Cristiane Deon¹, Danielle Maria de Souza Sérgio dos Santos², Roberta Alvarenga Reis³, Claudia Fegadolli⁴, Monika Bullinger⁵, Claudia Benedita dos Santos⁶

ABSTRACT

The objective of this study was to translate and make the cultural adaptation of the Brazilian version of the DISABKIDS® Atopic Dermatitis Module (ADM), an instrument used to measure the health-related quality of life of children and adolescents with atopic dermatitis. The instrument has 12 items answered using a Likert scale, with two versions: self and proxy. The study counted with a sample of 18 Brazilian children and adolescents with atopic dermatitis, of ages ranging between 8 and 18 years, and their respective parents or caregivers. The process involved the following steps of translation-back translation and semantic evaluation. The former revealed good acceptance of the translated version of the instrument, which participants considered having items of easy understanding. After completing the process of validation in the country, the instrument will become available to Brazilian researchers to measure health-related quality of life, as well as to compare results from Brazil to that of other cultures in which the instrument has already been validated.

DESCRIPTORS

Dermatitis, atopic
Child
Adolescent
Quality of life
Validation studies

RESUMO

O objetivo deste estudo foi traduzir e adaptar culturalmente para o Brasil o DISABKIDS® Atopic Dermatitis Module (ADM), instrumento para mensuração de qualidade de vida relacionada à saúde de crianças e adolescentes, com Dermatite Atópica. O instrumento possui 12 itens com respostas em escala do tipo Likert, com duas versões, self e proxy. A pesquisa incluiu uma amostra de 18 crianças e adolescentes brasileiros com Dermatite Atópica, na faixa etária de 8 a 18 anos, e seus respectivos pais ou cuidadores. O processo envolveu as fases de tradução-retrotradução e validação semântica. A validação semântica mostrou boa aceitação da versão traduzida do instrumento com fácil compreensão de seus itens pelos participantes. Após o término de seu processo de validação no país, o instrumento poderá ser utilizado por pesquisadores brasileiros para mensuração de qualidade de vida relacionada à saúde, bem como possibilitará comparação entre resultados no Brasil com outras culturas nas quais o instrumento já se encontra validado.

DESCRIPTORIOS

Dermatite atópica
Criança
Adolescente
Qualidade de vida
Estudos de validação

RESUMEN

Este estudio objetivó traducir y adaptar culturalmente para Brasil el DISABKIDS® Atopic Dermatitis Module (ADM), instrumento para medición de calidad de vida relacionado a salud de niños y adolescentes con Dermatitis Atópica. El instrumento posee doce ítems con respuestas en escala tipo Likert, con dos versiones: self y proxy. La investigación incluyó muestra de 18 niños y adolescentes brasileños con dermatitis atópica, en faja etaria de 8-18 años, y respectivos padres o cuidadores. El proceso involucró las fases de traducción-retrotraducción y validación semántica. La validación semántica mostró buena aceptación de la versión traducida del instrumento, con fácil comprensión de sus ítems por los participantes. Acabado su proceso de validación en el país, el instrumento podrá ser utilizado por investigadores brasileños para medición de calidad de vida relacionada a la salud. También posibilitará comparaciones entre resultados de Brasil con otras culturas en las que el instrumento ya se encuentra validado.

DESCRIPTORIOS

Dermatitis atópica
Niño
Adolescente
Calidad de vida
Estudios de validación

* The use of the DISABKIDS® instruments is protected by copyright. Authorization for this research was obtained from the DISABKIDS® GROUP, Hamburg – Germany ** Taken from the thesis “Cultural adaptation and validation of the specific Atopic Dermatitis module of the Health Related Quality of Life assessment instrument for children/adolescents – DISABKIDS®-ADM – Phase I”, University of São Paulo at Ribeirão Preto College of Nursing, 2009 ¹Physiotherapist. Ph.D. Student in Sciences from University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, SP, Brazil. keiladeon@usp.br ²Pharmacist. Ph.D. Student in Sciences from University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, SP, Brazil. dani.farma84@usp.br ³Speech, language and hearing therapist. Ph.D. in Public Health Nursing from University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, SP, Brazil. robfono@gmail.com ⁴Pharmacist. Ph.D. in Public Health Nursing from University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, SP, Brazil. Faculty, Universidade Metodista de Piracicaba. Piracicaba, SP, Brazil. cfegadol@unimep.br ⁵Psychologist. Ph.D. Professor at Universitätsklinikum Hamburg Eppendorf. Institut und Poliklinik für Medizinische Psychologie, Zentrum für Psychosoziale Medizin, Hamburg, Germany. bullinge@uke.uni-hamburg.de ⁶Ph.D. in Statistics. Associate Professor, Maternal-Infant and Public Health Nursing Department, University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, SP, Brazil. cbsantos@eerp.usp.br

INTRODUCTION

There has been plenty of interest in Quality of Life (QoL) lately. Despite the lack of consensus about its definition, it can be understood as satisfaction or happiness with life in view of the domains the person considers important⁽¹⁾.

As for Health Related Quality of Life (HRQoL), it is considered a health indicator that assesses a person's general physical condition, functional ability, housework activities, social interactions, cognitive function and emotional condition in relation to his health status⁽²⁾. HRQoL measurement instruments can facilitate clinical decision making, assess care quality, estimate a population's health service needs and understand the causes and consequences of health problems⁽³⁾.

The impact of chronic conditions of children and adolescents' QoL/HRQoL is important because both childhood and adolescence are periods of transformations in people's biological and psychosocial aspects. In this phase, the emergence of a chronic condition can generate alterations or physical and psychological limitations that affect the child or adolescent's growth and development. Difficulties in social relations and in the independence process in the parent-child relation can accompany these factors⁽⁴⁾.

One of these chronic conditions is Atopic Dermatitis (AD), a dermatological condition that can affect the skin to different extents. Characteristics include the presence of skin inflammation and pruritis, as well as reddish stains⁽⁵⁾. Besides the symptoms, the duration of this condition, its treatment and limitations in activities of daily living can entail considerable QoL changes for children or adolescents with AD⁽⁶⁾.

In line with research on subjective constructs and specifically QoL/HRQoL in children and adolescents with chronic conditions, it is interesting to consider the impact of AD on this population's physical, mental and social functioning. Thus, studying aspects beyond the condition's clinical parameters permits greater knowledge on the child or adolescent's health condition, in accordance with the global trend towards health humanization. Hence, in pediatrics, QoL/HRQoL measurement instruments need to be used with a view to indicators to direct actions aimed at comprehensive care delivery⁽⁷⁻⁹⁾.

A literature review in PubMed/Medline revealed that, among instruments for QoL/HRQoL measurement in AD patients, the only tool specifically aimed at measuring the HRQoL of school-age children and adolescents with AD is the DISABKIDS® Atopic Dermatitis Module (ADM). No studies are found on the cultural adaptation and validation of instruments for children and adolescents with AD in Brazil, although there is research based on translated versions⁽¹⁰⁾.

The DISABKIDS® Atopic Dermatitis Module (ADM) joins a set of HRQoL measurement instruments for the pediatric population with chronic conditions, developed by the European group DISABKIDS®. These instruments were developed from a cross-cultural perspective, involving seven European countries (Austria, Greece, France, the Netherlands, United Kingdom, Sweden and Germany). The DISABKIDS® Atopic Dermatitis Module (ADM) comprises 12 items in two specific dimensions: Impact and Stigma. The first includes eight items about the physical or emotional impacts of the condition. The second comprises four items related to feelings of stigmatization when other people look at the child or adolescent's skin condition⁽¹¹⁾. Two versions, self and proxy exist, for children and adolescents and parents or caregivers, respectively. The latter answer about HRQoL aspects of the child or adolescent they live with. The instruments are preferably self-applied and answers are shown on a Likert scale⁽¹²⁾.

Given the lack of this type of instrument in Brazil, this research, in collaboration with the European DISABKIDS® Group, aimed to translate and culturally adapt the DISABKIDS® Atopic Dermatitis Module (ADM) instrument, used to measure the HRQoL of children and adolescents, between 8 and 18 years of age, with AD.

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METHOD

This methodological research involves the search for new meanings, interpretations of phenomena and instrument development for data collection⁽¹³⁾ and consists of the translation and cultural adaptation of a HRQoL measurement instrument for children and adolescents with AD in Brazil.

Sample and place of data collection

The study population included Brazilian children and adolescents with AD, between 8 and 18 years of age, and their parents or caregivers. According to a dictionary⁽¹⁴⁾, proxy is defined as procurator, procurator, substitute, representative. In this research, proxy does not refer to the legal aspects, but to that person who lives with the child or adolescent at home and in the context of this research is called caregiver.

The study sample comprised 18 Brazilian children and adolescents, between 8 and 18 years of age, with a medical diagnosis of AD, and their parents or caregivers. Convenience sampling was used, as the participants were contacted according to their order of arrival for medical consultations at the Dermatology Service of the University of São Paulo Medical School *Hospital das Clínicas* - HCFMUSP. Although non probabilistic, the researchers took care to maintain homogeneity in terms of gender and age range. This kind of sample can be considered representative of

the care population at the service where the research was carried out⁽¹⁵⁾.

Ethical aspects of the study

Approval for this research was obtained from the Institutional Review Board for Research involving human beings at HCFMUSP, according to research protocol No 0160/09. Data were collected in April 2009 at the abovementioned service.

During all interviews, the Informed Consent Term (ICT) was read and signed and respondents received guarantees that their names would be kept strictly confidential. All parents and caregivers signed two copies of the ICT, one of which for the lead researcher and one for the parent/caregiver. It should be taken into account that, independently of the parents or caregivers' consent, children and adolescents who refused to participate were not obliged to do so.

Data collection instruments and procedures

Initially, parents or caregivers were contacted who accompanied their children and adolescents under outpatient follow-up at the described Dermatology Service, for inclusion in the sample. Next, age and presence of AD were verified. The research aims and instruments were presented. If the parents or caregivers and the children and adolescents decided to participate, the ICT was read and two copies were signed.

Then, the instruments were made available and procedures for completion were explained. The instruments were filled out while awaiting outpatient medical care. For the cultural adaptation process of the DISABKIDS® Atopic Dermatitis Module (ADM), according to the DISABKIDS® Group, the following instruments were used, which correspond to the contents of the Pilot Test Manual – DISABKIDS® GROUP⁽¹⁶⁾: a) DISABKIDS® Atopic Dermatitis Module (ADM), in its versions for children and adolescents (self) and parents or caregivers (proxy), translated to Brazilian Portuguese and adapted to the Brazilian culture; b) General Impression Instrument for semantic validation, including items like *what do you think about our general questionnaire? Are questions understandable? Are the questions important for your health condition? and c) Specific semantic validation instrument, with items like Is this important for your situation? Are answer options clear and consistent in accordance with the question? Can you tell me, in your own words, what this question means to you?*

Translation-back translation

The translation was the first phase of the adaptation and validation process of the DISABKIDS® Atopic Dermatitis Module (ADM). Two bilingual people with knowledge on the theme translated the instrument from English to Portuguese. The lead researcher and members of the research group in Brazil analyzed both versions, conciliated

the translations and defined a final version. Then, one bilingual person who was unfamiliar with the main theme elaborated the back translation.

Finally, the translation and back translation were subject to conciliation with the lead researcher of the project in Europe, with a view to cultural harmonization, and the terms of the instrument's final version were defined for children and adolescents and for parents and caregivers, in Brazil.

Semantic validation of DISABKIDS® Atopic Dermatitis Module (ADM)

Next, semantic validation was carried out, which serves to verify the understanding of existing DISABKIDS® Atopic Dermatitis Module (ADM) items (self and proxy) by interviewing the respondents. This phase aimed to identify problems related to the research subjects' understanding and acceptance of the terms.

For this phase of the cultural adaptation process, all 18 children and adolescents and their parents or caregivers answered the DISABKIDS® Atopic Dermatitis Module (ADM). Then, six groups were constituted, with two age groups (8-12 and 13-18 years) and the division of the 12 ADM instrument items in three sub-sets: sub-set A, with items 1 to 4, sub-set B, with items 5 to 8 and sub-set C, with items 9 to 12. For each group, three participants were considered, totaling 18 children and adolescents and their respective parents or caregivers.

Thus, the items were assessed according to meaning, importance and understanding, based on the participants' answers to the General Impression instrument and the specific semantic validation instrument.

The DISABKIDS® Group proposes the division in sub-groups for the semantic validation phase with a view to guaranteeing answer reliability, as a detailed analysis of all instrument items in terms of importance and understanding, by the same child or adolescent or his/her respective parent or caregiver, can be a large and exhaustive task.

RESULTS

The DISABKIDS® Atopic Dermatitis Module (ADM) was translated to Brazilian Portuguese for use in the semantic validation phase according to the DISABKIDS® Group's proposal⁽¹⁷⁾, described in the methods section. This process took two months.

After the translation and back translation, the coordinator of the DISABKIDS® project compared the back-translated conciliated version with the original version and gave a favorable opinion. This terminated the final version in Brazilian Portuguese of the DISABKIDS® Atopic Dermatitis Module (ADM), called DISABKIDS – specific Atopic Dermatitis module (DISABKIDS-MDA), used in the subsequent phase.

As mentioned, 18 children and adolescents and their respective parents or caregivers participated in the semantic validation phase, without any refusals. Table 1 displays

the participants' socio-demographic characteristics according to the children and adolescents' age range in years.

Table 1 - Socio-demographic characteristics of children and adolescents, fathers or caregivers who participated in the semantic validation of the DISABKIDS® Atopic Dermatitis Module (ADM), according to the children and adolescents' age range - Brazil - 2009

Characteristics		8 to 12 years		13 to 18 years	
Children and adolescents					
Age (years)	\bar{x} /SD	8.5	0.7	14.5	1.5
No brothers/sisters	\bar{x} /SD	1.1	1.1	2	1
No years in school	\bar{x} /SD	2.7	1.0	8	2.2
Gender	Girls (n/%)	6		7	77.8
	Boys (n/%)	3		2	22.2
Parents or caregivers					
Age (years)	\bar{x} /SD	37.3	6.1	40.5	4.1
Respondents	Mother (n/%)	8		9	100
	Others (n/%)	1		0	0
Marital status	Married (n/%)	6		6	66.7
	Marital union (n/%)	3		1	11.1
	Separated (n/%)	0	0	1	11.1
	Single (n/%)	0	0	1	11.1
\bar{x} - Mean	SD - Standard Deviation				

The goal of this study phase was to identify possible problems to understand the instrument's items and answer categories, with a view to adjusting terms for adaptation to the Brazilian culture if necessary. Therefore, an interview was held, in which both children and adolescents and their parents or caregivers, who agreed to participate in the study after receiving information, signed two copies of the ICT and answered the abovementioned forms.

The analysis of answers to the General Impression instrument revealed that, in general, the participants accepted the DISABKIDS®-MDA well accepted and found it easy to understand. In total, 88.9% of the children and adolescents and 88.9% of parents or caregivers considered the instrument very good, and items were found relevant, easy to understand and with appropriate alternative answer categories for the chronic condition under analysis. The results are displayed in Table 2.

Table 2 - Assessment results for the General Impression part of the semantic validation phase of the DISABKIDS® Atopic Dermatitis Module (ADM) instrument for children and adolescents and their parents or caregivers, according to the respondent group - Brazil - 2009

Items from the General Impression Instrument	Alternative answers	Answer % children and adolescents (n = 18)	Answer % parents and caregivers (n = 18)
What did you think about our questionnaire in general?	Very Good	88.9	88.9
	Good	11.1	11.1
Are questions understandable?	Easy to understand	83.3	94.4
	Sometimes difficult	16.7	5.6
About the answer categories?]Did you have any difficulties?	No difficulty	83.3	83.3
	Some difficulties	16.7	16.7
Are the questions important for your health condition?	Very relevant	88.9	88.9
	Sometimes relevant	11.1	11.1

The instrument used in the specific semantic validation part was easily understood, except for some items. Among children between 8 and 12 years of age, 33.3% presented some level of difficulty to understand some instrument questions, such as *is this relevant for your situation?, how would you say/express this? (reformulation)*. In these cases, the researcher had to intervene and help by explaining the exact aim of each question in more colloquial terms.

The analysis of results for the specific semantic validation part for children and adolescents revealed that the understanding of item four in the DISABKIDS® Atopic Dermatitis Module (ADM) *does your skin condition affect your concentration in school?* was the item that most raised doubts among the children and adolescents and was not well understood, although 50% of the participants reports that pruritis or, in the children and adolescents' colloquial

language, itching, negatively affects their school performance, as they feel bothered and their concentration is hampered when studying.

Item seven, *does your skin condition affect your free time? (sports/games)*, showed no relevance for 50% of the children/adolescents, who consider that the presence of AD does not interfere considerably in their activities of daily living.

Also, 16.7% of the participants judge that items two *does the aspect of your skin bother you?*, three *does the itching bother you at night?*, five *does looking at your skin scare you?*, six *does your skin get worse when you are stressed?*, eight *are you uncomfortable with the way your skin is?*, nine *do you try to hide the situation of your skin?*, ten *does it bother you when people look at you strangely?* and twelve *do you feel uncomfortable when people look at you?* are not relevant for their condition. The possible explanation for this is that these respondents are in the remission phase of AD and have not had any skin injuries for a long time, nor pruritis, but are under follow-up to accompany the evolution and monitoring of AD.

Item 11 *you don't like it when your friends witness the application of your creams* aroused questions to the researcher, as none of the participants considered it relevant for the condition. The reason the participants alleged was that their creams are used at home only, like after bathing for example, so that other people cannot witness using them. This shows how the cultural issue is influential, as the Brazilian population does not commonly use creams or ointments in public.

As for answers on the specific semantic validation part for parents/caregivers, these were similar with the children/adolescents' answers. The average time necessary to answer the DISABKIDS® Atopic Dermatitis Module (ADM) was 15 minutes, for children and adolescents as well as for parents or caregivers. To answer the specific semantic validation instruments, parents or caregivers needed an average 20 minutes, while children and adolescents needed 30 minutes on average.

Both groups indicated that items four, seven and eleven raised doubts. This is so because, in their pre-semantic validation translated version, these items contained the term *the condition*, defined as the cause of doubt, as some participants did not understand its meaning. Regarding item four *does your child's skin condition affect his/her concentration in school?* four parents or caregivers affirmed that their children's school performance was considerable hampered due to the great severity of the AD and that, often, they are asked to visit the institutions where their children study to give information on their skin condition. They report that, often, people who do not know about the condition and its chronic and non contagious nature often misunderstand them and that the children and adolescents feel different from others, making them abstain from social contact, which reveals the weight of the stigma surrounding this condition. Regarding item eleven *doesn't your*

child like it when his/her friends witness the application of creams?, the parents or caregivers mentioned that the creams really are only applied at home, far from other people's eyes, an item that would not be relevant at all for a child or adolescent with AD.

In addition to these results, all children and adolescents and parents or caregivers reported no suggestions to modify the DISABKIDS® Atopic Dermatitis Module (ADM). One of the parents or caregivers, however, believes it is important to include an item on the child or adolescent's food, as AD is related with food allergies. Also, 27.8% of them mentioned that they wanted to discover the cure for their child or adolescent's condition.

After analyzing the results of this phase, the necessary judgments and alterations were made to adapt the DISABKIDS® Atopic Dermatitis Module (ADM) to a better level of understanding. Thus, the researchers found it necessary to replace the term *your skin condition* by a colloquial term *the way your skin is*, which was already used in item eight for example. This alteration was made in items four and seven after a favorable opinion by the DISABKIDS® project coordinator in Europe.

DISCUSSION

In initial research, the QoL of people living with chronic conditions was assessed in terms of survival and signs of presence of the condition. Today, this panorama has changed and, besides the impact of symptoms and treatment, the people's physical, emotional and psychosocial aspects started to be valued⁽¹⁸⁾. Due to the greater need and importance of measuring QoL/HRQoL in recent decades, construction, cultural adaptation and validation processes of instruments aimed as measuring subjective constructs has increased exponentially⁽¹⁹⁾, permitting result comparisons in multicenter studies⁽²⁰⁾.

For the pediatric population with chronic conditions, this context deserves special attention. After all, children and adolescents in the physical, mental and social development phase are obliged to live with conditions and treatments that can extend across their lifetime, like in the case of AD. Among dermatological conditions affecting children and adolescents, AD exerts the greatest negative impact on people living with chronic conditions and their relatives, similar to what happens with type 1 diabetes⁽¹⁰⁾.

There are few QoL/HRQoL measurement instruments for children and adolescents with AD and, today, there is no specific instrument for use in Brazil. Hence, an instrument was needed for this population. Therefore, in this study, internationally adopted procedures were followed for the cultural adaptation and validation of instruments to measure subjective constructs.

In this context, the introduction of methods like HRQoL assessment in clinical practice permits comprehensive

knowledge on the subject's condition, in which HRQoL measurement instruments are aspects for consideration in clinical studies that assess the effect of new treatment modalities and their possible impact on participants' QoL, besides the objective data expected in a clinical trial. In this sense, some authors have highlighted the importance of measuring QoL and establishing it as an outcome indicator in health programs and interventions, beyond research⁽²¹⁾.

Every day, health professionals interact with children and adolescents who go through situations of anxiety and discomfort due to chronic conditions. The responsibility to relieve symptoms and enhance patients' comfort demands the assessment of physical, physiological, emotional, behavioral and environmental aspects that influence the child's condition. Thus, in pediatrics, QoL assessment instruments need to be used as indicators to direct actions with a view to comprehensive care delivery.

In the cultural adaptation and validation process of the DISABKIDS[®] Atopic Dermatitis Module (ADM), in the semantic part, the children and adolescents and their parents or caregivers self-applied the instruments, followed by an interview, during which the understanding and acceptance of the terms deriving from the translation process were verified. As a result, 83.3% of the children and adolescents considered the items easy to understand and the answer categories adequate, providing answers without any difficulty.

Children and adolescents with severe levels of AD took more time to answer and showed to be more silent and tending to avoid interaction with the researcher. It is described in literature that children and adolescents with AD present sleep disorders due to the pruritis, pain, fatigue, irritability and aversion to social interaction⁽²²⁾, which may have hampered their participation.

It was observed, however, that children at the age of eight showed greater difficulty and took more time to answer the instruments. Authors have reported that younger children are fully able to describe their wellbeing and functional ability when the instrument is created in view of the target population's age and cognitive level, and also that some difficulties can emerge for children who are learning to read and write or who face reading and writing difficulties^(2,9). In this particular case, the problem was related to the number of years in school, as children with greater difficulties to answer the instrument were exactly those who had attended school for less years, corresponding to 33.3% of children between 8 and 12 years of age.

Hence, it is recommended that the instrument be used in view of the children's literacy level, so as to avoid language, reading and writing problems.

For 94% of the parents or caregivers, the version used showed to be understandable, and 88.8% considered the

instrument very good and with highly relevant items for their children and adolescents' condition.

Based on the interview, it was verified that the term *condition of your skin* was not easy to understand, which is why it was replaced by *the way your skin is*, which was the only adjustment needed to proceed with the final self and proxy versions of the DISABKIDS[®]-MDA in Brazilian Portuguese.

It is important to take into account that, in a country as large as Brazil, different cultural contexts can be identified, which can affect the adaptation and validation process of instruments that measure subjective constructs like HRQoL. Thus, Brazilian children and adolescents can be developing in diverse cultural and social context in one and the same nation. The sample involved in this study comprised different ethnic groups and socio-economic classes and, therefore, may also be influenced by different life and education habits. This is considered an important factor in the analysis, as impressions about the instrument were similar inside a group with the abovementioned differences, as the instrument needs to have a broad range for children and adolescents with AD.

CONCLUSION

This study included 18 Brazilian children and adolescents with AD and their parents or caregivers. Its goal was the translation and cultural adaptation of the DISABKIDS[®]-ADM in Brazil. Procedures to achieve these goals followed international literature, using standardized phases in accordance with the DISABKIDS[®] Group method.

This study permitted multidisciplinary contact, involving physiotherapists, statisticians, physicians, nurses, psychologists, pharmacists and speech, language and hearing therapists, which was fundamental for the cultural adaptation process of an instrument that serves to measure a subjective health-related construct. As this instrument is directed at children and adolescents with a condition as peculiar as AD, different professionals' involvement permitted greater knowledge on the several aspects involved.

The study of QoL/HRQoL and cultural adaptation and validation methods of measurement instruments is a growing trend in Brazil. The relevance of these procedures is particularly evidenced when related to CC as, today, health care is directed at comprehensive care delivery, which values individuals as active participants in this process. After analyzing its psychometric properties and terminating its validation process in Brazil, the researchers hope that Brazilian researchers will use the DISABKIDS[®]-ADM and compare its results with those from other cultures, and also incorporate the tool as an auxiliary instrument in health professionals' daily clinical practice, with a view to monitoring health conditions over time and discovering the impact of their interventions on the condition and evolution of Brazilian children and adolescents with AD.

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