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Preliminary psychometric assessment of the Brazilian version of the DISABKIDS[®] Atopic Dermatitis Module

ABSTRACT

OBJECTIVE: To assess preliminary psychometric properties of the Brazilian Portuguese version of a questionnaire for measuring health-related quality of life in children and adolescents with atopic dermatitis.

METHODS: Cross-sectional study with a sample consisting of 52 children and adolescents aged 8 to 18 diagnosed with atopic dermatitis, and their parents or caregivers, selected at the dermatology department of a university hospital in the city of São Paulo, Southeast Brazil, in 2009. Construct validity, internal consistency and agreement between the responses of children and adolescents and their parents or caregivers were assessed in the Brazilian Portuguese version of the DISABKIDS[®]-Atopic Dermatitis Module (ADM).

RESULTS: Adequate internal consistency was found with Cronbach's alpha coefficients of 0.7024/0.8124 and 0.7239/0.8604. The multitrait multimethod analysis for assessing convergent validity showed measures higher than 0.30 for all items. The analysis showed good discriminant validity. Agreement between child self-report and parent proxy-report was evaluated using intra-class correlation with measures impact and social stigma of disease of 0.8173 and 0.7629, respectively.

CONCLUSIONS: The study results showed that the DISABKIDS[®]-ADM can be used by Brazilian researchers after its complete validation as it showed adequate preliminary psychometric properties and can be considered a valid, reliable instrument.

DESCRIPTORS: Dermatitis, Atopic, psychology. Quality of Life. Child. Adolescent. Validation Studies.

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INTRODUCTION

The impact of health on quality of life (QoL) has been historically discussed. Human and biological science research has been focused on understanding and assessing factors other than symptom control, reduced mortality and increased life expectancy.¹⁰ Subjective constructs such as personal values, skills, satisfaction and well-being have been the focus of attention of health researchers.¹¹

Although there is no consensus on the definition of QoL, it can be understood as a satisfaction or happiness in core domains of one's life. The World Health Organization defines QoL as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.²⁴

Health-related quality of life (HRQoL) refers to the subjective and objective impact of some dysfunctions associated with the individuals' disease states and health treatment.¹² In the past QoL/HRQoL of individuals living with chronic conditions used to be assessed in terms of survival and the presence of signs of these conditions. But it has changed and today it is assessed based not only on the impact of symptoms and treatment, but also on physical, emotional and psychosocial aspects.^{7,14} According to Fayers and Machin⁸ (2007), the conceptual framework of HRQoL includes aspects such as general health, physical and emotional symptoms, functional losses, and social, sexual and existential well-being. As a result, the processes of construction, cultural adaptation and validation of instruments for measuring QoL/HRQoL have increased exponentially in recent years.¹

Studies of QoL/HRQoL have been traditionally conducted with adults. However, in the last two decades the focus of QoL/HRQoL research has shifted to children and adolescents.^{1,2} Wallander et al²¹ (2001) in a literature review found 20,000 articles on QoL/HRQoL, of which only 3,050 focused on children.

Atopic dermatitis is a chronic relapsing skin condition characterized by skin inflammation and severe itching that affects individuals' daily activities and sleep and involves costs for medication, treatment and disease control.¹⁵ It predominantly develops during childhood and affects individuals with a family history of asthma, rhinitis and atopic dermatitis. People with chronic dermatitis suffer the impact of these conditions on physical, mental and social domains of life, adversely affecting their daily living activities, interpersonal relationships as well as their finances.⁴ Skin conditions are a source of stigma in societies that overvalue physical appearance.

Children and adolescents suffering from chronic conditions deserve special attention as they are going through physical, mental and social development and may have to cope with these conditions and treatments throughout their lifetime.¹⁶ This is the case of patients with atopic dermatitis. Among all skin conditions that affect children and adolescents, atopic dermatitis is the one condition that causes the greatest adverse impact on QoL/HRQoL, comparable to that of type 1 diabetes.²³

QoL/HRQoL measuring instruments can be valuable tools for clinical decision-making and can help assessing quality of care, treatment effectiveness, and health-related needs and understanding the causes and consequences of health problems.^{3,18}

The DISABKIDS® Atopic Dermatitis Module (ADM) is the only QoL/HRQL measuring instrument for schoolchildren and adolescents with atopic dermatitis. Although there are studies on generic versions of the

DISABKIDS® ADM, no studies have been conducted on cultural adaptation and validation of this instrument specifically in Brazilian children and adolescents with atopic dermatitis.²³

The present study aimed to assess preliminary psychometric properties of the Brazilian Portuguese version of the HRQoL measuring instrument in children and adolescents with atopic dermatitis.

METHODS

A cross-sectional study was carried out with data collected during May and August 2009 at the dermatology department of a university hospital in the city of São Paulo, southeast Brazil. The study sample consisted of 52 children and adolescents, aged eight to 18 years, diagnosed with atopic dermatitis, and their parents and caregivers. Convenience, non-probability sampling was used but care was taken to have a similar distribution of sex and age group.

The exclusion criterion was lack of minimal cognitive ability of children, adolescents, parents and caregivers to understand the instrument's questions. Their cognitive skills were assessed based on medical records, researcher's observation, medical and/or parents and caregivers reporting.

Children and adolescents were selected by sex and age group (eight to 12 years; 13 to 18 years). They were divided into four groups of 13 children/adolescents in each group according to the DISABKIDS® protocol.^{6,9}

The DISABKIDS® ADM consists of 12 items pertaining to two dimensions: impact and stigma. The impact dimension comprises eight items on physical or emotional impact of atopic dermatitis. The stigma dimension consists of four items related to children's and adolescents' feelings of being stigmatized when their skin appearance is negatively judged.⁶ A mean standardized score is obtained for each dimension ranging from zero to 100, with zero being associated with the greatest negative impact of atopic dermatitis on HRQoL and 100 with the lowest negative impact. Two versions of DISABKIDS® are available: the self-report version (child and adolescent version) and the proxy version (parent and caregiver version). It is preferably self-administered and responses are given in a Likert-type scale.¹⁷ Medical records of the children and adolescents studied were reviewed for clinical information on their condition. Then the DISABKIDS®-ADM self-report and proxy versions, translated and culturally adapted into Brazilian Portuguese, were administered.⁵ With respect to the instrument's preliminary psychometric properties, a previous study¹⁴ reported floor and ceiling effects, i.e., when more than 15% of the responses pile up in the lowest (0%) or highest (100%)

score, which may indicate impaired responsiveness of the instrument.⁸ The minimum sample size to identify floor and ceiling effects is 50 respondents.²⁰

Convergent and discriminant validity was used to assess the instrument's construct validity. Ware et al²² (1988) Multitrait Analysis Program (MAP) was used to perform a multitrait multimethod analysis to assess correlations between items and dimensions. Acceptable correlations for convergent validity are 0.30 for preliminary validation studies and higher than 0.40 for final validation studies.⁸

Discriminant validity was performed using three different methods. First, a MAP analysis assessed the percentage of times that the correlation of a particular item with a pertaining dimension was greater than or statistically greater than its correlation with a non-pertaining dimension, called "adjustment".⁸ Second, mean scores of severity of atopic dermatitis were analyzed after verifying normality of the distribution of sample means for each group through the Kolmogorov-Smirnov test. The analysis of variance (ANOVA) followed by multiple comparison test of Bonferroni were performed. Third, Pearson linear correlation between scores assigned to the instrument items A, B and C and impact and stigma dimension scores was performed. These three last questions A, B and C refer to the children's and adolescents' and their parents' and caregivers' perception of the severity of atopic dermatitis. The answers to these questions can be used to group children and adolescents according to disease severity, and mean scores can be correlated with the dimensions of impact and stigma for assessing the instrument's discriminant validity.

Swiscow¹⁹ (1997) criteria were used to assess the strengthen of linear correlation, as proposed in studies of DISABKIDS® instruments: 0.00 to 0.19, very weak or no correlation; 0.20 to 0.39, weak correlation; 0.40 to 0.59, moderate correlation; 0.60 to 0.79, strong correlation; and 0.80 to 1, very strong correlation.

Cronbach's alpha was used to assess the instrument's reliability and values above 0.70 were considered acceptable, as proposed by Terwee et al²⁰ (2007).

Parents' responses are no substitute for children's and adolescents' since they tend to underestimate their HRQoL. Although the children's and adolescents' responses are the standard for measuring HRQoL, in some circumstances they cannot be obtained, as in cases where children are too young, do not have adequate cognitive skills, or are too ill or tired. Thus, to assess the level of agreement between of children's and adolescents' and their parents' and caregivers' responses intraclass correlation coefficient (ICC) was used as follows: lower than 0.40, weak correlation; 0.40 to 0.60, moderate correlation; 0.60 to 0.80, good

or substantial correlation; and higher than 0.80, near perfect or very good correlation.^{8,13,22} This was adopted because systematic differences between responses that would not be taken into account when using the Pearson correlation coefficient are likely.

Data was double entered to avoid potential errors. SPSS version 10.0 was used in the analysis. The level of significance was 5% ($\alpha = 0.05$).

The study was approved by the Human Research Ethics Committee at Hospital das Clínicas of Faculdade de Medicina da Universidade de São Paulo (research protocol n°. 0160/09). An informed consent form was read and signed for all respondents and strict confidentiality was assured. Even with their parents' and caregivers' consent, children and adolescents who refused to participate were not forced to do it.

RESULTS

The mean age of children aged eight to 12 was 9.6 years (standard deviation [SD] 1.1) and of those aged 13 to 18 was 14.35 years (SD 1.4). The sample had a similar gender distribution. The mean age of parents and caregivers of children aged eight to 12 years was 38.1 years (SD 7.1) and of those aged 13 to 18 was 42.7 years (SD 6.8).

As for other medical conditions besides atopic dermatitis, 73.1% and 80.8% of children and adolescents aged eight to 12 and 13 to 18 had allergic rhinitis, and 34.6% and 42.3% had asthma, respectively. Atopic dermatitis, asthma and allergic rhinitis were the "atopic triad."

With regard to the severity of atopic dermatitis, among children aged eight to 12, 23.1% had mild, 57.7% moderate and 19.2% severe disease. Among adolescents aged 13 to 18, 42.3% had mild, 34.6% moderate and 23.1% severe disease.

Floor and ceiling effects were not seen in the impact and stigma dimensions, which suggests the instrument's responsiveness.

As for convergent validity of the DISABKIDS® ADM, Table 1 presents Pearson correlation coefficients between the items and each dimension in the pilot test for the DISABKIDS® ADM. Correlation coefficients were greater than 0.30; most were greater than 0.40.

The negative linear correlation between item 8 and its dimension both for children and adolescents and parents and caregivers (-0.65 and -0.81, respectively, Table 1) indicate that inconsistency. For field testing, another semantic validation process should be used to assess this item's content.

Regarding DISABKIDS® ADM internal consistency

Table 1. Convergent validity of the Brazilian version of the DISABKIDS® ADM in the multitrait-multimethod analysis. São Paulo, Southeastern Brazil, 2009.

Item	Children and adolescents		Parents and caregivers	
	Impact	Stigma	Impact	Stigma
	Rc	Rc	Rc	Rc
1	0.77	0.60	0.76	0.75
2	0.56	0.65	0.78	0.76
3	0.79	0.53	0.72	0.68
4	0.64	0.50	0.85	0.76
5	0.60	0.56	0.65	0.65
6	0.50	0.39	0.44	0.51
7	0.53	0.50	0.58	0.67
8	-0.65	-0.69	-0.81	-0.76
9	0.64	0.62	0.83	0.73
10	0.51	0.68	0.80	0.84
11	0.36	0.48	0.48	0.47
12	0.48	0.77	0.68	0.80

Rc: Corrected item-total correlations

Table 2. Reliability of the Brazilian version of the DISABKIDS® ADM. São Paulo, Southeastern Brazil, 2009.

Item	Cronbach's alpha if the item was excluded	
	Children and adolescents	Parents and caregivers
Impact		
1	0.5900	0.6279
2	0.6363	0.6125
3	0.5814	0.6339
4	0.6188	0.5914
5	0.6340	0.6481
6	0.6468	0.6910
7	0.6445	0.6628
8	0.8736	0.8998
Total α	0.7024	0.7239
Stigma		
9	0.7697	0.8105
10	0.7438	0.7623
11	0.8284	0.9054
12	0.6963	0.7791
α total	0.8124	0.8604

Table 2 shows the values for Cronbach's alpha according to the impact and stigma dimensions in children and adolescents and parents and caregivers. Overall, the coefficient was adequate for the impact and stigma dimensions both for children and adolescents and parents and caregivers. The instrument showed good internal consistency, with homogeneity among the

items to measure HRQoL of children and adolescents with atopic dermatitis.

The ICC values of responses between children and adolescents and their parents and caregivers were 0.82 and 0.76 for the impact and stigma dimensions, respectively.

According to the criteria adopted, the ICC value for the size impact is considered very good or near perfect, to the extent stigma is considered good or substantial. These results show that there is a considerable level of agreement between the responses of children and adolescents and parents and caregivers, especially for the size impact.

The discriminant validity of the instrument at this stage is presented in Table 3, where results are observed "fit" positive.

Mean standardized scores, standard deviations and coefficients of variation of the impact dimension according to disease severity in children and adolescents were respectively: 73.8, 8.4, and 11.4% for mild; 51.5, 14.6, and 28.3% for moderate; and 35.7, 10.9, and 30.5% for severe disease. The following results were found for the stigma dimension: 83.4, 23.7, and 28.4% for mild; 55.7, 23.7, and 42.5% for moderate, and 34.0, 20.9, and 61.5% for severe disease.

Among parents and caregivers, the following results were found for the impact dimension: 68.1, 14.2, and 20.9% for mild; 42.9, 16.4, and 38.2% for moderate; and 32.9, 10.30, and 31.3% for severe disease. The results for the stigma dimension were: 83.4, 21.7, and 26.0% for mild; 48.1, 25.1, and 52.2% for moderate, and 27.8, 20.9, and 75.2% for severe disease.

The ANOVA showed statistically significant differences in mean scores of both the dimensions of impact and stigma in children or adolescents across all disease severity categories ($F_{2,51} = 35.029$, $p < 0.001$ and $F_{2,51} = 15.922$, $p < 0.001$, respectively). Among parents and caregivers there was found statistically significant differences between mild, and moderate and severe disease, but there no statistically significant difference was found between moderate and severe disease groups for both the dimensions of impact and stigma ($F_{2,51} = 23.125$; $p < 0.001$ and $F_{2,51} = 21.279$, $p < 0.001$, respectively).

Table 4 presents Pearson linear correlation coefficients (r) and related p -values between response scores of children and adolescents and their parents and caregivers in items A, B and C and each dimension of the DISABKIDS® ADM. It was found a moderate-to-strong correlation between the scores in items A, B and C and the impact and stigma dimension, confirming the discriminant validity of the DISABKIDS® ADM.

Table 3. Discriminant validity of the Brazilian version of the DISABKIDS® ADM in the multitrait-multimethod analysis. São Paulo, Southeastern Brazil, 2009.

Variable	Children and adolescents				Parents and caregivers			
	Impact		Stigma		Impact		Stigma	
	n items	%	n itens	%	n itens	%	n itens	%
-2	1	12.5	0	0.0	1	12.5	0	0.0
-1	1	12.5	1	25.0	2	25.0	2	50.0
1	6	75.0	2	50.0	5	50.0	2	50.0
2	0	0.0	1	25	0	0.0	0	0.0
Adjustment		75.0		75.0		50.0		50.0

Table 4. Discriminant validity for scores in items A, B and C and the dimensions of impact of stigma of the Brazilian version of the DISABKIDS® ADM. São Paulo, Southeastern Brazil, 2009.

Variable	Children and adolescents				Parents and caregivers			
	Impact		Stigma		Impact		Stigma	
	r	p-value	r	p-value	r	p-value	r	p-value
A	-0.546	0.000	-0.555	0.000	-0.695	0.000	-0.642	0.000
B	-0.609	0.000	-0.543	0.000	-0.565	0.000	-0.530	0.000
C	-0.465	0.001	0.417	0.002	-0.401	0.003	-0.346	0.012

r: Pearson correlation coefficient

p-value: probability associated with the test

DISCUSSION

The study showed that the dimensions of impact and stigma of the DISABKIDS® ADM had good/substantial (0.81) and very good/almost perfect reliability (0.70).²⁰ The European version of this instrument had a reliability of 0.87 and 0.71 for impact and stigma, respectively.¹ Although lower than those found in the European version, our results are acceptable for both dimensions.

Convergent and discriminant validity was used to assess the construct validity in this study. Convergent validity was quite satisfactory with 100% of the correlations greater than 0.30, which is ideal for preliminary studies.⁸

The discriminant power of the instrument was assessed using three different approaches. Mean standardized scores and their related standard deviations of DISABKIDS® ADM were described according to disease severity, and they showed good ability to discriminate children and adolescents with mild, moderate, and severe atopic dermatitis. Similarly, the MAP analysis showed good correlation of items with their related dimension in children and adolescents (75% adjustment for both dimensions). On the other hand, in parents and caregivers, lower results were found, with 50% adjustment for both dimensions, showing a weaker correlation between items and their related dimension. These results were unexpected; however, it is expected that in the field test with more participants it will be closer to the desirable 100%.

A moderate to strong correlation was found between correlation coefficients and scores in items A, B and C and the dimensions of impact and stigma in both children and adolescents, and parents and caregivers.

DISABKIDS® ADM is not only the single instrument for measuring QoL/HRQoL in schoolchildren and adolescents with atopic dermatitis but also has the advantage of being available in two versions, a child self-report and a proxy one. It is essential to know the level of agreement between the responses of children and adolescents and their parents and caregivers in order to know whether the latter can provide reliable information on their children's QoL/HRQoL. The agreement between the self-report and proxy versions was quite good, with results higher than those found in the validation of the instrument in Europe.¹

No floor and ceiling effects were seen in the present study. The original European version of the instrument showed a ceiling effect around 46% in the stigma dimension.⁶ It is a very relevant aspect of the instrument's responsiveness, an important feature for detecting small clinical changes in children and adolescents.

Based on the study findings the DISABKIDS® ADM can be validated and reliable so that it could be made available after field testing for Brazilian researchers to assess QoL/HRQoL in children and adolescents with atopic dermatitis.

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