

Cross-culturally adaptation of the knowledge of disease management-cf-adolescent questionnaire into Brazilian Portuguese

Adaptação transcultural do questionário knowledge of disease management-cf-adolescent para o português-brasileiro

Adaptación transcultural del cuestionario knowledge of disease management-cf-adolescent al portugués brasileño

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ABSTRACT | This study cross-culturally adapted the Knowledge of Disease Management-CF-Adolescent (KDM-CF-Adolescent) questionnaire into Brazilian Portuguese and tested its measurement properties. Cross-cultural adaptation followed five standardized steps: translation, consensus on the translated version, back translation, consensus on the back translation version, and application of the final version to 35 adolescent patients aged 11 to 20 years with cystic fibrosis (CF). Due to the COVID-19 pandemic and social distancing measures, the questionnaire was delivered online using the Google Forms platform. Data underwent Rasch analysis using the WINSTEPS software. Since no issues regarding understanding were reported, we made no changes in any of the translated items. KDM-CF-Adolescent divided the sample into two levels of knowledge and the items into three levels of difficulty, leading to person and item reliability indices of 0.67 and 0.81, respectively, and internal consistency of 0.69. All items fit the Rasch model expectations since all infit/outfit and associated z values were within the expected range. Principal component analysis confirmed the existence of two dimensions; however, they did not function as independent scales. Analysis showed

no duplication of any content and no floor and/or ceiling effects. The Brazilian Portuguese version of the KDM-CF-Adolescent questionnaire showed satisfactory measurement properties in measuring the knowledge of adolescents with CF about the disease.

Keywords: | Cystic Fibrosis; Patient Health Questionnaire; Knowledge Management; Health Knowledge, Attitudes, Practice; Healthy Lifestyle.

RESUMO | O objetivo desse estudo foi adaptar o questionário *Knowledge of Disease Management-CF-Adolescent* (KDM-CF-Adolescent) de forma transcultural para o português brasileiro, bem como testar suas propriedades de medida. A adaptação transcultural seguiu cinco passos padronizados: tradução, versão consenso traduzida, tradução reversa, versão consenso da tradução reversa e aplicação da versão final a 35 adolescentes com Fibrose Cística (FC) entre 11 e 20 anos. Devido às medidas de isolamento social impostas pela pandemia de covid-19, a aplicação do questionário foi realizada de forma on-line, pela plataforma Google Forms. As respostas do questionário foram submetidas à

Study developed at the Physical Therapy Department of the Universidade Federal de Minas Gerais (UFMG) and Associação Mineira de Assistência a Mucoviscidose (AMAM) – Belo Horizonte (MG), Brazil.

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análise Rasch, usando o software WINSTEPS. Como não houve problema de entendimento das questões, não foi necessário alterar nenhum dos itens traduzidos. O questionário KDM-CF-*Adolescent* dividiu a amostra em dois níveis de conhecimento e os itens em três níveis de dificuldade, levando a índices de confiabilidade dos indivíduos e dos itens de 0,67 e 0,81, respectivamente e consistência interna de 0,69. Todos os itens atenderam às expectativas do modelo Rasch, uma vez que todos os valores de *infit/outfit* e *z* associados estavam dentro do intervalo esperado. A análise de componentes principais confirmou a existência de duas dimensões; no entanto, elas não funcionaram como escalas independentes. Não houve duplicação de nenhum conteúdo nem efeitos teto e/ou chão. A versão brasileira do questionário demonstrou propriedades de medidas satisfatórias, para medir o conhecimento que os adolescentes com FC têm sobre a doença.

Descritores | Fibrose Cística; Questionário de Saúde do Paciente; Gestão do Conhecimento; Conhecimento de Saúde, Atitudes, Prática; Estilo de Vida Saudável.

RESUMEN | El objetivo de este estudio fue realizar una adaptación intercultural del cuestionario *Knowledge of Disease Management-CF-Adolescent* (KDM-CF-Adolescents) al portugués brasileño, así como probar sus propiedades de medición. La adaptación intercultural siguió cinco etapas estandarizadas: traducción, versión

consensuada traducida, traducción inversa, versión consensuada de traducción inversa y aplicación de la versión final a 35 pacientes adolescentes con fibrosis quística (FQ) de entre 11 y 20 años de edad. Debido a las medidas de aislamiento social impuestas por la pandemia de la covid-19, el cuestionario se aplicó en línea mediante la plataforma Google Forms. Las respuestas al cuestionario se enviaron al análisis Rasch en el *software* WINSTEPS. Como no hubo problemas para comprender las preguntas, no fue necesario realizar cambios en ninguno de los elementos traducidos. El cuestionario KDM-CF-Adolescents dividió la muestra en dos niveles de conocimiento; y los ítems en tres niveles de dificultad, lo cual dio como resultado índices de confiabilidad de individuos e ítems de 0,67 y 0,81, respectivamente, y la consistencia interna de 0,69. Todos los ítems cumplieron con las expectativas del modelo Rasch, ya que todos los valores de *infit/outfit* y *z* asociados estaban dentro del rango esperado. El análisis de los componentes principales confirmó la existencia de dos dimensiones; sin embargo, estas no funcionaron como escalas independientes. No hubo duplicación de ningún contenido ni efectos de piso y/o techo. La versión brasileña del cuestionario KDM-CF-Adolescents demostró propiedades de medidas satisfactorias para evaluar el conocimiento que los adolescentes con FQ tienen sobre la enfermedad.

Palabras clave | Fibrosis Quística; Cuestionario de Salud del Paciente; Gestión del Conocimiento; Conocimiento de Salud, Actitudes, Práctica; Estilo de Vida Saludable.

INTRODUCTION

Cystic fibrosis (CF) is an autosomal recessive genetic disorder caused by mutation of the chromosome 7 gene, known as cystic fibrosis membrane regulator (CFTR) which is the protein that regulates the transport of ions, chlorine, sodium, and bicarbonate, essential for transporting salt and water through the cell membrane in the exocrine glands. Nowadays, CF is diagnosed at birth by the heel prick test^{1,2}.

Given the early diagnosis and disease severity, respiratory and nutritional preventive care are needed. Treatment is conducted by a multidisciplinary team throughout individuals' lives. The approach changes, according to the age group and severity³⁻⁵. Despite advances in treatment, CF has no cure and efforts and resources are directed towards preventing complications, especially those related to the respiratory system which unfortunately destroy the lungs and lead to premature death⁴⁻⁸.

At the beginning of treatment care is performed by parents or guardians, but over the years the patients must acquire autonomy to manage their own care, especially during adolescence. Considering that adolescence is a period of difficult maturation and the beginning of responsibility for 2 to 3 hours of daily treatment⁶, measuring the knowledge acquired by individuals throughout the treatment years is necessary.

Considering that knowledge is an important process of education and intervention⁷ that can lead to the prevention of complications, verifying what patients know about their disease and self-care is important, especially in adolescence when they are encouraged to be responsible for their own care⁹. To address this issue, a previous study¹⁰ developed an educational program to foster self-management by identifying the needs and then organizing practical activities involving individuals with CF and their families. Other two studies^{6,11} found that gaps in knowledge about the disease played an important role in treatment adherence.

Given the importance of learning preventive measures, the “I change adherence and rise expectations” (iCARE)^{12–14} group developed the Knowledge, Skills, and Adherence Measure of CF for assessing the knowledge of both adolescent with CF and their caregivers about the disease, as it can interfere with management and treatment adherence.

Hence the creation of the 35-item Knowledge of Disease Management-CF-Adolescent (KDM-CF-Adolescent) questionnaire for the population aged 11 to 20 years. Bernstein et al.¹⁵ assessed item difficulties and discrimination, reliability, and validity of the questionnaire with 266 adolescents from several reference US CF centers. They reduced the questions to 23 to reduce application time (10 to 15 minutes), making it more clinically useful¹⁵. The questionnaire may assist both health professionals and individuals with CF in building a path to prevent complications and improve self-care during treatment.

In Brazil, the multidisciplinary team who work with individuals with CF lacks access to instruments for evaluating the knowledge that Brazilian adolescents with CF have about the disease. Thus, for this study cross-culturally adapted the 23-item version of the KDM-CF-Adolescent questionnaire into Brazilian Portuguese and verified its measurement properties using the Rasch analysis model.

METHODOLOGY

Individuals with CF of both sexes, from 11 to 20 years, who were registered at the Associação Mineira de Assistência a Mucoviscidose (AMAM), were invited to participate. Recruitment occurred between November, 2020 and May, 2022. All participants and/or their caregivers provided written consent prior to data collection.

Cross-cultural adaptation of the KDM-CF-Adolescent questionnaire followed standardized procedures^{16–18} and was carried-out in five stages, as follows: 1) the questionnaire was translated from English into Brazilian Portuguese independently by two bilingual translators, whose native language is Portuguese; 2) the two translated versions were discussed between the translators and an expert committee composed of three physical therapists to produce a consensus synthesis version; 3) the synthesis version underwent back-translation which was conducted independently by two other bilingual translators,

whose native language is English. They did not have access to the original version, nor were they informed about the concepts of the questionnaire; 4) an expert committee composed of three physical therapists, one translator and one back-translator consolidated all versions of the questionnaire and developed the pre-final version; 5) the pre-final version was administered to 35 adolescents with CF, who answered the questionnaire and were asked to interpret each question and point out possible understanding difficulties. As there was no issues regarding wording and clarity of the items, the final version of the KDM-CF-Adolescent-Brazil was established (Appendix 1).

First contact with potential participants and their families were established via phone, when they were asked about their interest in participating. All participants were screened for eligibility and received explanations about the study. Demographic and clinical information, including forced expiratory volume in one second (FEV₁) data, over the previous six months were obtained from their medical records for characterization purposes. The second contact occurred via email to collect data regarding schooling, physical activity practice (considered as performing exercises regularly), hospitalization over the last year and use of medication, especially antibiotics. During the third contact, the KDM-CF-Adolescent-Brazil questionnaire was applied online using Google Forms. Participants who did not return the emails after four contacts were excluded.

Sample description used descriptive statistics. Clinical utility evaluation of the KDM-CF-Adolescent-Brazil used the Tyson and Connell¹⁹ scale, a 4-item instrument related to time of administration/interpretation, cost, equipment/specialized training needs, and portability. Scores range from 0 to 3 (items 1 and 2) and from 0 to 2 (items 3 and 4), scoring up to 10. Higher scores indicate clinical utility and scores ≥ 9 indicate that the test can be recommended to clinical practice²⁰. To quantify the time of administration, participants were asked to report the time they took to fill out all the questionnaire.

Data underwent Rasch analysis which enables evaluating the quality of the responses according to a probabilistic model, in which the probability of choosing a response depends only on the individual's ability and the items difficulty²¹. Analysis was performed by WINSTEPS (version 5.2.2.0) and the following measurement properties were verified:

Reliability: internal consistency and both person and item separation coefficients were used to estimate the

number of strata within the range of the participants' abilities and item difficulties²¹. The number of strata was calculated using the following equation: Number of strata = $(4G+1)/3$, in which "G" is the separation coefficient²². It was expected the participants to be stratified into at least two strata (low and high levels of knowledge), which would imply a person reliability index >0.80 , and that the items into at least three levels of difficulty (low, medium, and high). Reliability indices >0.60 are acceptable, >0.80 adequate, and >0.90 excellent²².

Unidimensionality: biserial point, principal component analysis (PCA), and fit statistics criteria²¹ were adopted. Biserial point refers to the correlation between a given item and the total scores, the value of which should be >0.50 . To examine how well the items fitted the model expectations, goodness-of-fit statistics were considered in two formats, infit and outfit (MnSq) in combination with standardized Z values (Z-score)²¹. The critical values for a Type 1 error rate of 5% were calculated by the following equation, which considered the influence of the sample size: $MnSq(\text{infit})=1+2/\sqrt{x}$; $MnSq(\text{outfit})=1+6/\sqrt{x}$, in which "x" is the sample size²¹. Items with $MnSq > \text{critical values}$ in combination with $Z > 2$ indicated that the responses were erratic, i.e., misfit (14). More than 5% of the total number of the items being erratic is a great threat to construct validity because it indicates that the items do not combine to measure a unidimensional construct²³. The same fit statistics and criteria were used for assessing person fit.

For the PCA, the criteria used were that the principal component should explain at least 50% of the total residual variance and, after its removal, a second large dimension should explain less than 5% of the remaining variance or show an eigenvalue $<2^{22,24}$. If a second dimension is identified, it is necessary to evaluate whether its size and nature would justify a separate analysis²¹.

Local independence: the success or failure in one item is not dependent on the score in another. High correlations between the residuals of two items ($r > 0.7$) indicate that they are not independent, since the pair of items share more than half of the variance ($V > 0.49$) and, thus, only one would suffice²².

Item-person map: this is a visual representation of the level of knowledge about CF, in which both items and individuals are displayed along the same linear continuum²⁵. This enables investigating whether the KDM-CF Adolescent-Brazil items were appropriate

for the levels of knowledge of the sample, ceiling/floor effects, and gaps^{21,25}.

RESULTS

A total of 35 adolescents (23 males) with a mean age of 15.7 years (SD 3.1) participated in the study. Table 1 summarizes their descriptive data.

Table 1. Participant characteristics

Characteristic		n=35
Age (years), mean \pm SD (minimum-maximum)		15.7 \pm 3.1 (11-20)
Sex (male), n (%)		23 (65.7)
Schooling, n (%)	Elementary	13 (37.1)
	Middle	21 (60)
	High	1 (2.9)
Body mass index (m/kg ²)		20.2 \pm 3.8 (13-31.6)
Physical activity (yes), n (%)		25 (71.4)
Hospitalization (yes), n (%)		14 (40)
Predicted VEF ₁ (n=21) mean \pm SD		72.1 \pm 14.7
Pancreatic insufficiency (yes), n (%)		25 (71)
Antibiotic use		
One, n (%)		15 (43)
Two, n (%)		4 (11)
None, n (%)		16 (46)
KDM-CF- Adolescent - Brazil (scores), mean \pm SD (minimum-maximum)		13 \pm 4.4 (4-20)

SD: standard deviation; kg/m²: kilograms per square meter; FEV₁: forced expiratory volume in one second; KDM-CF-Adolescent-Brazil: Knowledge of disease management-Cystic Fibrosis-adolescent Brazil.

Clinical utility

Based on Tyson and Connells' criteria, clinical utility of the KDM-FC-Adolescent-Brazil was ensured since it scored 9 points (Table 2). The only item that affected the score was application time (between 15 and 20 minutes).

Table 2. Clinical utility of the KDM-CF-Adolescent-Brazil questionnaire, based on Tyson and Connell's (2009) criteria

Item	Criteria	Score
Time for administration, analysis and interpretation	< 10 minutes: score 3	2
	10 to 30 minutes: score 2	
	30 to 60 minutes: score 1	
	60 minutes: zero score	
Cost	< 100 Brazilian reais: score 3	3
	to 500 Brazilian reais: score 2	
	500 to 1,000 Brazilian reais: score 1	
	1,000 Brazilian reais: zero score	
Need for equipment and training	No: score 2	2
	Yes, but it is simple, easy to use and requires no specialized training: score 1	
	Yes: zero score	
	Yes, it fits in a bag: score 2	
Portability	Yes, it fits in a briefcase or cart: score 1	2
	No: zero score	
KDM-FC-Adolescent-Brazil total score		9

KDM-CF-Adolescent-Brazil: Knowledge of disease management-Cystic Fibrosis-adolescent Brazil.

Rasch analysis showed:

Reliability: the items were distributed into three levels of difficulty, resulting in a 0.81 item reliability index. Person separation analysis indicated two levels of knowledge, obtaining a 0.67 person reliability index. Internal consistency was 0.69.

Unidimensionality: all items met the Rasch model expectations since all Infit/Outfit values were within the expected range. However, item 12 showed negative biserial point and deserves attention. We found no predictable items since all MnSq values were >0.6 in both Infit/Outfit formats²⁶. Table 3 shows the calibration of the KDM-CF-Adolescent-Brazil items in a decreasing order of difficulty, with the associated error values. Item 13 (Food that contains the most energy/calories are) was the most difficult and item 18 (with cystic fibrosis, the cough), the easiest. Despite the adequate MnSq values, PCA revealed that the principal component explained only 24.6% of the variance with an eigenvalue of 7.49. These results suggest the existence of a second dimension, separating the questionnaire in two group of items. Subsequent analyses of the two sub-scales revealed that they did not work well independently, given the decrease in separation indices, reliability, and internal consistency values. Thus, it seems that measurement of separated dimensions is not justified.

Table 3. Calibration of the KDM-CF-Adolescents-Brazil items in decreasing order of difficulty

Item	Calibration n (logits)	Error (logits)	Infit		Outfit		Serial Point
			MnSq	ZSTD	MnSq	ZSTD	
13. Foods that contain the most energy/calories are:	2.77	0.55	0.99	0.11	1.14	0.42	0.22
3. Which of the following is a sign that your body is losing too much salt?	1.52	0.40	0.97	-0.09	0.86	-0.42	0.39
8. To make the most of your clinic visit, you should:	0.93	0.37	0.93	-0.49	0.87	-0.63	0.45
10. Stress, lots of homework or problems with a friend can affect your:	0.93	0.37	0.99	-0.02	0.95	-0.19	0.38
15. Timing is everything; what is the right order to take the following treatments?	0.79	0.37	0.98	-0.11	1.01	0.12	0.38
2. Most of the food you eat is absorbed in the:	0.39	0.37	0.95	-0.39	0.88	-0.71	0.45
4. Inhaled antibiotics are generally most effective if done:	0.39	0.37	1.08	0.70	1.14	0.83	0.28
11. Exercise can replace regular airway clearance.	0.26	0.37	1.16	1.32	1.19	1.08	0.21
17. When you feel stressed, it may help to:	-0.26	0.37	0.84	-1.37	0.76	-1.44	0.56

(continues)

Table 3. Continuation

Item	Calibration n (logits)	Error (logits)	Infit		Outfit		Serial Point
			MnSq	ZSTD	MnSq	ZSTD	
6. When you exercise, you should:	-0.01	0.37	0.90	-0.70	0.86	-0.68	0.48
23. People with CF take vitamins A, D, E, and K because these vitamins:	-0.01	0.37	1.25	1.76	1.33	1.60	0.11
1. Pulmonary function tests (PFT) are fancy name for tests that:	-0.15	0.38	0.88	-0.85	0.84	-0.77	0.50
9. How can you decrease the number of lung infections you get?	-0.15	0.38	0.95	-0.33	0.91	-0.39	0.43
20. Being open and talkative with your CF Team is important because:	-0.30	0.38	0.85	-0.95	0.75	-1.11	0.54
16. Teens with CF should eat:	-0.45	0.39	0.85	-0.88	0.83	-0.62	0.51
12. Changes in your mucus, cough, or energy levels:	-0.60	0.40	1.31	1.54	1.59	1.88	-0.01
14. Your CF team will check your blood glucose:	-0.60	0.40	1.17	0.90	1.06	0.31	0.22
19. One way to add calories to scrambled eggs is:	-0.60	0.40	1.11	0.62	1.09	0.39	0.26
21. To keep from getting new CF bacteria in your lungs, you should:	-0.60	0.40	0.79	-1.15	0.69	-1.15	0.58
22. Teens with CF need to eat more because:	-0.60	0.40	1.04	0.25	1.13	0.53	0.30
7. If your body is not digesting fat from the foods you eat, your stool may:	-0.95	0.43	0.87	-0.50	0.74	-0.71	0.49
5. Stomach cramps and gases can be signs of hunger and:	-1.60	0.51	1.03	0.20	0.72	-0.42	0.34
18. With CF, cough:	-1.60	0.51	1.16	0.56	2.07	1.76	0.05
Mean	0.00	0.40	1.00	0.01	1.02	-0.01	

Local independence: no correlations occurred between the items >0.70, indicating that all items were locally independent, i.e., they do not duplicate content and therefore the response to one does not interfere with another.

Item-person map: it (Figure 1) represents the continuum of knowledge about CF, showing the relation between the calibration of the level of difficulty for the questionnaire items and the measures of knowledge of the sample. The vertical line depicts the continuum of knowledge, as defined by the items, organized by levels of difficulty on the right. On the left, the participants were distributed and organized by their levels of knowledge. Analysis showed a difference of only 0.45 logits between the average measure of knowledge and the average measures of difficulty. Thus, most of the items fell in the

middle third of the continuum, as did the ability of most participants. The items were relatively well distributed throughout the continuum, but five (12, 14, 19, 21, and 22) were calibrated at the same levels of difficulty. Harder items congregated at the top of the continuum and easy items at the bottom, but both levels had no participants. No floor or ceiling effects were found since none of the participants obtained 100% of correct or incorrect responses. Looking closer at the data, the maximum score of 20 (out of 23) was achieved by two participants (5.8%) and the minimum score of 4 was achieved by only one participant (2.9%). These results, together, confirm the absence of floor and ceiling effects. Five questions related to self-care (3, 8, 10, 13, and 15) had less than 50% of correct responses, with question 13 having the lowest number of correct answers (1.4%).

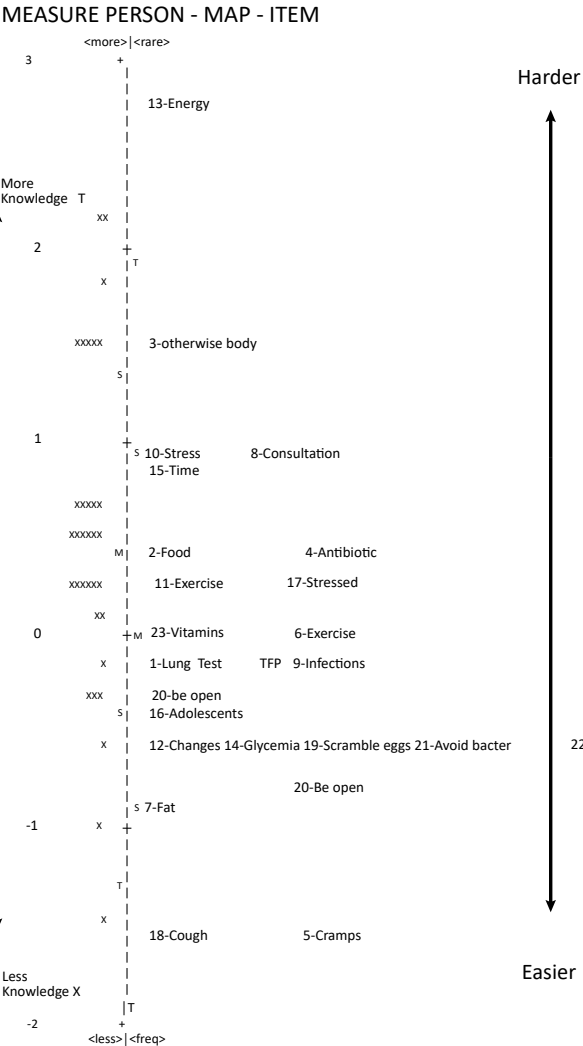


Figure 1: Representative map of the item distribution in relation to participants' levels of knowledge. WINSTEPS (version 5.2.2.0).

DISCUSSION

This study cross-culturally adapted into Brazilian Portuguese the KDM-CF-Adolescent, a questionnaire for assessing the knowledge of adolescents with cystic fibrosis about the disease. Cross-cultural adaptation followed standardized procedures^{16,17} and required no adjustments or modifications in any of the items to enable understanding. The measurement properties of the adapted version was evaluated by Rasch analysis which is considered a robust approach²⁷. This analysis converts ordinal data into interval measurements, verifies measurement invariance and errors of the item, and orders the items and individuals in a linear continuum, showing that the probability of answering an item correctly depends only on its difficulty or the individual's ability²⁸.

Reliability is the instrument's ability to indicate when people or items are estimated having high

abilities, when they are really high, or when they are estimated as having low abilities, when they are really low²². Analysis found adequate reliability coefficients for the items (0.81); however, reliability for the individuals was 0.67. Although reliability values below 0.80 are not the most adequate²², values above 0.60 are acceptable²⁸. Internal consistency was 0.69, a little lower than the values of 0.76 and 0.78 reported by Bernstein et al.¹⁵ for the original version applied to 133 individuals with CF. According to Linacre²², the small sample size could explain the lower reliability coefficients found in our study.

Rasch analysis found no erratic or unpredictable patterns for the answers²⁹, revealing that the items were independent. Considering that none of the participants scored 100% of correct or incorrect answers, no ceiling (maximum score) or floor (minimum score) effects were found. When ceiling effect occurs, the measure is limited

and decreases the probability of the test to accurately measure the intended domain and detect changes over time. Presence of ceiling or floor effects can influence important measurement properties such as sensitivity and responsiveness³⁰.

Another important point for the cross-cultural adaptation process is comprehension. After applying the pre-final version no modifications were necessary, following the basic principle that the questions are easy to understand and equivalent to the original version^{16,17}.

Items were organized satisfactorily and none was erratic, without fluctuations in the two Infit/Outfit formats, meeting the expectations of the Rasch model. However, the main component explained only 24.6% of the variance with an eigenvalue of 7.49, suggesting more than one dimension which compromises unidimensionality^{22-24,26,29}. However, this division is consistent with the original questionnaire which has two dimensions related to knowledge of CF treatment and self-care. Subsequent analysis revealed that the two dimensions did not behave as independent sub-scales, since when analyzed separately the separation indices, reliability, and internal consistency showed reduced values. Thus, it seems that the measurement of separated dimensions would not be justified.

Bernstein et al.¹⁵, when performing initial psychometric evaluation of the KDM-CF-Adolescent with 133 CF patients, also found two dimensions using exploratory factor analysis. The subscales were entitled self-care and knowledge of the disease. Internal consistency for the self-care sub-scale was 0.74, whereas for the knowledge subscale it was 0.68 with a total calculated measure of 0.78. Reliability was 0.73 and 0.65 for self-care and knowledge, respectively, with a total measure of 0.76.

According to the established criterion ($r > 0.7$), none of the items showed local dependency. This indicated that no item duplicated the content of another or that the response to one item did not interfere with that of another. Question 13 (Food that contains the most energy/calories are) was considered the most difficult and question 18 (With Cystic Fibrosis, cough) the easiest.

Evaluation of clinical utility of the KDM-CF-Adolescent-Brazil (Tyson and Connell¹⁹ criteria) resulted in a score of 9. The only item that affected the score was related to application time (between 15 and 20 minutes). This indicates that the questionnaire can be recommended for clinical practice²⁰, helping professionals to identify and intervene in the patient's knowledge of the disease and self-care.

Previous studies have shown that CF patients frequently have doubts concerning diet, both because of the discomfort of ingesting enzymes before meals and lack of knowledge regarding the influence of medication on food absorption, acting on pancreatic and intestinal insufficiency. Another neglected point is the relation between CF and pulmonary function^{2-4,28}.

Kazmerski et al.³⁰ monitored 38 adolescents (13 to 22 years old) for two years and observed that only eight used nutritional supplementation and six were at nutritional risk with body mass index (BMI) of 33. Although our study did not obtain data on nutrition, 12 of the 35 participants had BMI values below the desired (< 18.5). This corroborates the high percentage of errors (89%) on question 13 (Food that contains the most energy/calories are). Regarding the questions related to respiratory care, our sample showed better knowledge, but ignored the order they should follow to perform care, since 57% of the patients answered question 15 "Timing is everything; what is the right order to take the following treatments?" wrong. These findings should serve as a warning to the multidisciplinary team to increase educational actions related to nutrition and respiratory interventions.

This study is not without limitations. First, the small sample of only patients registered in AMAM may not reflect the national reality. Second, due to the COVID-19 pandemic and social distancing measures, it was not possible to conduct in-person interviews which may have limited the researchers' perceptions of the participants' understanding. However, all participants were literate and most had complete secondary education. In addition, patient adherence to the treatment could not be assessed. Third, our outcomes refer to a preliminary analysis. Future studies should include a larger and more diverse sample and evaluate other important measurement properties such as test-retest reliability, responsiveness, and sensitivity. However, this was the first step towards developing a multicenter project involving adolescents with CF from across the country to continue the KDM-CF-adolescent-Brazil validation process.

In summary, cross-cultural adaptation of the KDM-CF-Adolescent questionnaire into Brazilian Portuguese was conducted and the adapted version showed good clinical utility, satisfactory measurement properties, and absence of floor and/or ceiling effects. Adolescents with CF had greater difficulty with questions related to the self-care domain given the high percentage of errors in questions related to nutrition and respiratory issues. Results suggest that the KDM-CF-Adolescent-Brazil

questionnaire could be used in clinical and research contexts to measure the knowledge that adolescents with CF have about the disease. Future studies should apply the questionnaire to a larger CF population to access other important measurement properties.

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