

Cross-cultural adaptation of the knowledge of disease management-CF-adolescent questionnaire for 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 aimed to cross-culturally adapt the Knowledge of Disease Management-CF-Adolescent (KDM-CF-Adolescent) questionnaire for Brazilian Portuguese, as well as to test its measurement properties. Cross-cultural adaptation followed five standardized steps: translation; consensus version of the translation, back translation, consensus version of back translation, and application of the final version to 35 adolescent patients with cystic fibrosis (FC), aged 11 to 20 years. Due to the COVID-19 pandemic and social isolation measures, the questionnaire was applied online using the Google Forms. Data were subjected to Rasch analysis, using the WINSTEPS software. There were no problems regarding understanding the questions, so making changes in any of the translated items was not necessary. The 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. The principal component analysis confirmed the existence of two dimensions; however, they did not function as independent scales. There was no duplication of any

content and no floor and/or ceiling effects were found. The Brazilian Portuguese version of KDM-CF-Adolescent questionnaire demonstrated satisfactory properties to measure the knowledge adolescents with CF have about the disease.

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

RESUMO | O objetivo desse estudo foi adaptar transculturalmente o questionário *Knowledge of Disease Management-CF-Adolescent* (KDM-CF-Adolescentes) para a língua portuguesa falada no Brasil, 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 pacientes adolescentes com Fibrose Cística (FC) com idade 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 submetidos à análise de Rasch, usando o *software WINSTEPS*. Como não houve problema de entendimento das questões, não

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houve necessidade de fazer alterações em nenhum dos itens traduzidos. O questionário KDM-CF-Adolescentes 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 chão e/ou teto. A versão brasileira do questionário KDM-CF-Adolescentes 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 transcultural del cuestionario *Knowledge of Disease Management-CF-Adolescent* (KDM-CF-Adolescents) al portugués brasileño, así como probar sus propiedades de medición. La adaptación transcultural siguió cinco pasos estandarizados: Traducción, traducción consensuada, traducción reversa, traducción consensuada de la traducción reversa 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 sometieron al análisis Rasch en el *software* WINSTEPS. Como no hubo problemas para comprender las preguntas, no fue necesario realizar cambios en ninguno de los ítems traducidos. El cuestionario KDM-CF-Adolescentes 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 lo esperado en el 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-Adolescentes demostró propiedades de medidas satisfactorias para medir el conocimiento que tienen los adolescentes con FQ acerca de la enfermedad.

Palabras clave | Fibrosis Quística; Cuestionario de Salud del Paciente; Gestión del conocimiento; Conocimiento de la salud, actitudes, práctica; Estilo de vida saludable.

INTRODUCTION

Cystic Fibrosis (CF) is an autosomal recessive genetic disease caused by the mutation of the chromosome 7, 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 foot test^{1,2}.

Given the early diagnosis and severity of the disease, it is necessary to start a respiratory and nutritional preventive care. Treatment is conducted by a multidisciplinary team throughout individuals lives. The approach changes based on the age group and severity of the condition³⁻⁵. Despite advances, CF has no cure; most efforts and resources are directed to the prevention of complications, especially those related to the respiratory system, which unfortunately destroy the lungs and lead to premature death⁴⁻⁸.

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

Considering that knowledge is an important process of education and intervention⁷, that can lead to the prevention of complications, it is important to verify what individuals know about their disease and self-care, 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 aiming at stimulating self-management, identifying the needs and then organizing practical activities involving individuals with CF and their families. Other two studies^{6,11} showed that gaps in knowledge about the disease played important role in treatment adherence.

Due to 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 the assessment of the knowledge of both adolescent with CF and their caregivers about the disease, considering that it can interfere with management and treatment adherence.

The 35-item of the Knowledge of Disease Management-CF-Adolescent (KDM-CF-Adolescent) questionnaire was created for the population aged 11 to 20 years. Bernstein et al.¹⁵ assessed the item difficulties and discrimination, reliability, and validity of the questionnaire in 266 adolescents from several reference American CF centers. They reduced the questions to 23, so that it could be applied in less 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 does not have access to any instruments for the evaluation of the knowledge our adolescents hold about the disease. Therefore, this study aimed to cross-culturally adapt the 23-item version of the KDM-CF-Adolescent questionnaire for Brazilian Portuguese and verify the measurement properties of the adapted version, based on the Rasch analysis model.

METHODOLOGY

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

Cross-cultural adaptation of the KDM-CF-Adolescent questionnaire followed recommended procedures¹⁶⁻¹⁸ and was conducted in five stages, as follows: 1) the questionnaire was translated from English into Brazilian Portuguese, independently, by two bilingual translators, whose native language was Portuguese; 2) the two translated versions were discussed between the translators and an expert committee composed of three physical therapists, to create a consensus synthesis version; 3) the synthesis version was back-translated, which was conducted independently by two other bilingual translators, whose native language was English. Neither

had access to the original version, nor were informed about the concepts of the questionnaire; 4) following, 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) Finally, the pre-final version was administered to 35 adolescents with CF, who responded the questionnaire and were asked to interpret each question and indicate possible understanding difficulties. As there was no problem regarding wording and items clarity the final version, the KDM-CF-Adolescent-Brazil, was established (Appendix 1).

At first, potential participants and their families were contacted via telephone, 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 data on forced expiratory volume in one second (FEV₁) over the previous six months were obtained from the medical records, for characterization purposes. Then, participants were contacted via e-mail to collect data regarding schooling, physical activity practice (based on participants' report of regular exercise practice), 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 the Google Forms. Participants who did not return the e-mails after four contacts were excluded.

Descriptive statistics were used to describe the sample. Clinical utility evaluation of the KDM-CF-Adolescent-Brazil was based on Tyson and Connell (2009)¹⁹ scale, which contains four items addressing time of administration/interpretation, cost, need for equipment/specialized training, and portability. Scores range from 0 to 3 (items 1 and 2) and from 0 to 2 (items 3 and 4), totaling 10 points. Higher scores indicate clinical utility and scores ≥ 9 indicate that the test can be recommended to clinical practice²⁰. To address time of administration, participants were asked to report on the time necessary to fill out all the questions in the questionnaire.

Data were subjected to Rasch analysis, enabling the evaluation of the quality of the answers, according to a probabilistic model, in which the probability of choosing a response depends only on the individual's ability and the difficulty of items²¹. The WINSTEPS software (version 5.2.2.0) was used to analyze the data and various measurement properties were verified, as follows:

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

the number of strata within the range of the observed individuals' abilities and item difficulties²¹. To estimate the number of strata, the following equation was employed: Number of strata=(4G+1)/3, in which "G" is the separation coefficient²². It was expected that the individuals were 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 were stratified 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: The following criteria²¹ were adopted: biserial point, principal component analysis (PCA), and fit statistics. Biserial point refers to the correlation between a given item and the total scores, whose value should be >0.50. To examine how well the items fit the model expectations, goodness-of-fit statistics were considered in two formats, infit and outfit (MnSq) in combination with standardized Z-values (Zstd)²¹. The critical values for a Type 1 error rate of 5% were calculated by the following equations, which considered the influence of the size of the sample: MnSq (infit)= $1+2/\sqrt{x}$; MnSq (outfit)= $1+6/\sqrt{x}$, in which "x" is the sample size²¹. Items with MnSq>critical values in combination with Z>2 indicated that the responses were erratic, i.e., misfit (14). When more than 5% of the total number of items are erratic, this is a great threat to the construct validity, as it indicates the items do not combine to measure a

unidimensional construct²³. The same fit statistics and criteria were used for the examination of person fit.

For the PCA, the principal component should explain at least 50% of the total residual variance and after removing this component, 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: 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 be enough²².

The 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 the investigation of 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 individuals (23 boys), who had a mean age of 15.7 years (SD 3.1), participated. Table 1 summarizes their descriptive data.

Table 1. Characteristics of the participants

Parameter		n=35
Age (years), mean±SD (minimum-maximum)		15.7±3.1 (11-20)
Sex (males), 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 ±3.8 (13-31.6)
Physical activity (yes), n (%)		25 (71.4)
Hospitalization (yes), n (%)		14 (40)
VEF, % of predicted (n=21) mean±SD		72.1±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±SD (minimum-maximum)		13±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-Cistic Fibrosis-adolescent Brazil.

Clinical utility

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

Table 2. Clinical utility of the knowledge of disease management-Cystic Fibrosis-adolescent Brazil questionnaire, based on Tyson and Connell (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 BRL: score 3	3
	to 500 BRL: score 2	
	500 to 1,000 BRL: score 1	
	1,000 BRL: zero score	
Need for equipment and training	No: score 2	2
	Yes, but it's 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-FC-Adolescent-Brazil: Knowledge of disease management-Cystic Fibrosis-adolescent Brazil; BRL: Brazilian Reals.

The Rasch analysis showed:

Reliability: the items were distributed into three levels of difficulty, leading to a 0.81 item reliability index. The person separation analysis indicated two levels of knowledge, leading to 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. Notably, item 12 showed negative biserial point and deserves attention. No predictable items were found, 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 error values associated with the calibration on each item. Item 13 (Food that contain the highest quantity of energy/calories are) was the most difficult and item 18 (with cystic fibrosis, the cough) was the easiest. Despite the adequate MnSq values, the PCA revealed that the explained variance of the principal component was only 24.6% with a 7.49 eigenvalue. These results suggest the existence of a second dimension, separating the questionnaire into two groups of items. However, subsequent analyses of the two sub-scales revealed that they did not work well independently, since there were decreases in the separation indices, reliability, and internal consistency values. Therefore, it seems that measurement of separated dimensions would not be justified.

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

Items	Calibration n (logits)	Error (logits)	Infit		Outfit		Serial Point
			MnSq	ZSTD	MnSq	ZSTD	
13. Foods that contain the highest quantity of energy/calories are:	2.77	0.55	0.99	0.11	1.14	0.42	0.22
3. Which of the following options 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 doctor's appointment, you should:	0.93	0.37	0.93	-0.49	0.87	-0.63	0.45
10. Stress, too much homework or problems with a friend can affect yours):	0.93	0.37	0.99	-0.02	0.95	-0.19	0.38
15. Time is everything; what is the right order to do 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:	0.39	0.37	0.95	-0.39	0.88	-0.71	0.45
4. To inhale antibiotics are usually more effective if they are made:	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 can help:	-0.26	0.37	0.84	-1.37	0.76	-1.44	0.56
6. When you exercise, you should:	-0.01	0.37	0.90	-0.70	0.86	-0.68	0.48
23. People with Cystic Fibrosis 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) is the name used by physicians 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 communicative with your Cystic Fibrosis team is important because:	-0.30	0.38	0.85	-0.95	0.75	-1.11	0.54

(continue)

Table 3. Continuation

Items	Calibration n (logits)	Error (logits)	Infit		Outfit		Serial Point
			MnSq	ZSTD	MnSq	ZSTD	
16. Adolescents with Cystic Fibrosis should eat:	-0.45	0.39	0.85	-0.88	0.83	-0.62	0.51
12. Changes in your mucus, and cough or energy levels:	-0.60	0.40	1.31	1.54	1.59	1.88	-0.01
14. Your Cystic Fibrosis 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 avoid acquiring new bacteria in your lungs, you should:	-0.60	0.40	0.79	-1.15	0.69	-1.15	0.58
22. Adolescents with Cystic Fibrosis 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. Cramps in the stomach and gases can be signs of hunger and:	-1.60	0.51	1.03	0.20	0.72	-0.42	0.34
18. With Cystic Fibrosis, 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 between the items >0.70 were found, indicating that all items were locally independent, i.e., they do not duplicate some content, and therefore, the response to one does not interfere with that to another.

The item-person map: This (Figure 1) represents the continuous of knowledge about CF, showing the relationship between the calibration of the level of difficulty of the items of the questionnaire and the measures of knowledge of the sample. The vertical line illustrates 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. There was a difference of only 0.45 *logits* between the average measure of knowledge of the participants and the average measures of the difficulty of the items. Thus, most of the items fell in the middle third of the continuum, in

which the ability of most individuals was also located. 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. At the top of the continuum, it can be seen the absence of individuals without aligned items and at the bottom, very easy items, but there were not any individuals with such low levels of knowledge in the sample. No floor or ceiling effects were found, since none of the participants had 100% correct or incorrect responses. Looking closer to 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 regarding self-care (3, 8, 10, 13, and 15) had less than 50% of correct responses, being question 13 the one with the lowest number of correct responses (1,4%).

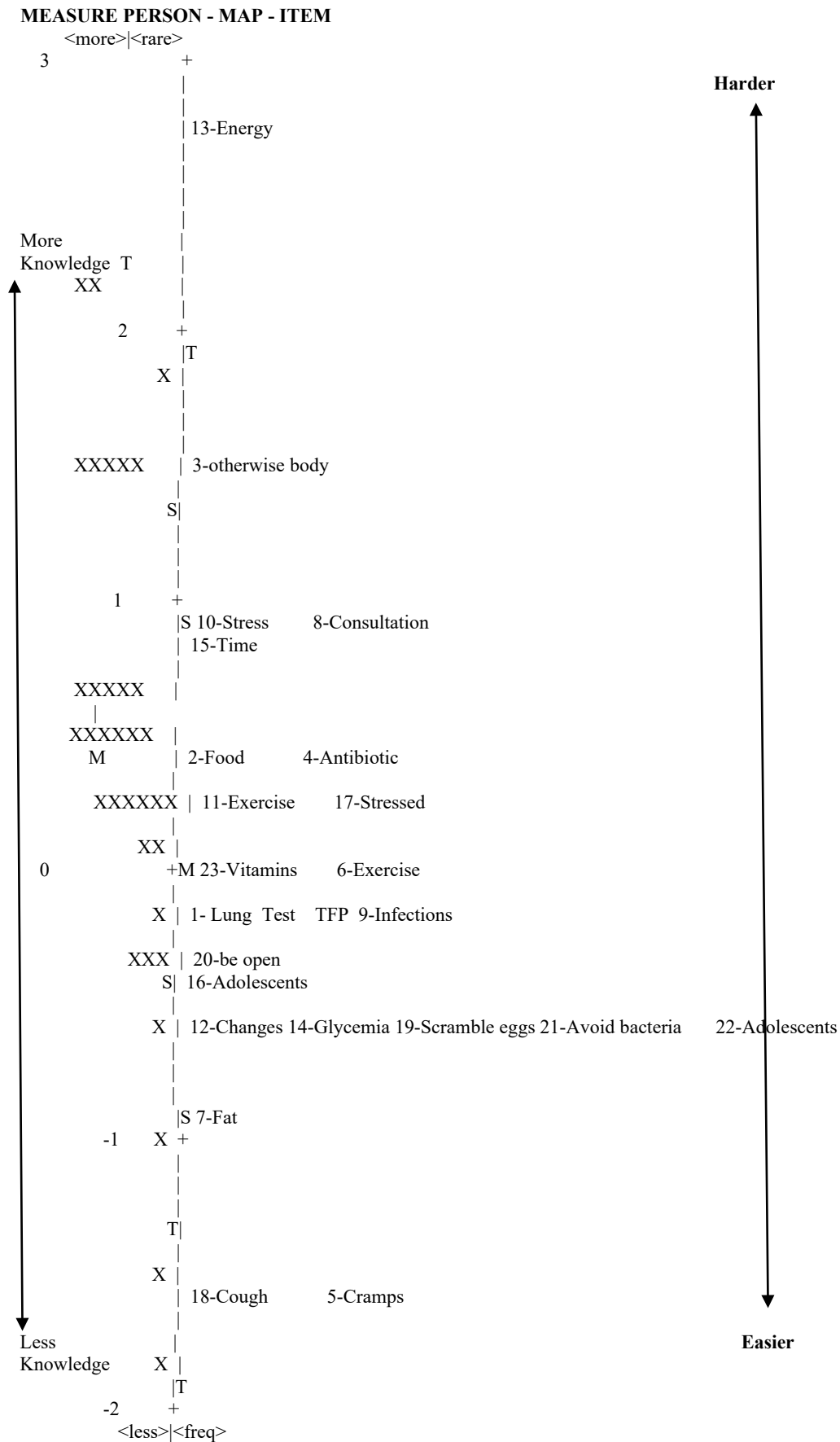


Figure 1. Representative map of the item distribution in relation to the individuals' levels of knowledge. WINSTEPS (version 5.2.2.0)

DISCUSSION

This study aimed to cross-culturally adapt the KDM-CF-Adolescent for the Brazilian Portuguese, a questionnaire for the assessment of knowledge that adolescents with CF have about the disease. Cross-cultural adaptation followed standardized procedures^{16,17} and no adjustments or modifications were necessary in any of the items. Evaluation of the measurement properties of the adapted version was performed by Rasch analysis, which is considered a robust approach²⁷. This analysis converts ordinal data into interval measurements, verifies the invariance of the measurement and the errors of the item, and orders the items and individuals in a linear continuum, showing that the probability of being successful on an item depends only on its difficulty or individuals' knowledge²⁸.

Reliability represent the instrument ability in indicating when people or items are estimated to have high abilities, when they are too high, or when they are estimated as having low abilities, when they are too 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 consistent was 0.69, which was a little lower than the values of 0.76 and 0.78 reported by Bernstein et al. (2018)¹⁵ for the original version with 133 individuals with CF. Based on Linacre²², it is likely that the reduced sample could justify the lower reliability coefficients found in our studies.

Rasch analysis revealed that there were no erratic or unpredictable patterns of the answers²⁹, the items were independent. Considering no participant obtained 100% of correct or incorrect answers, no ceiling or floor effects were established. 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. Floor effect was also not observed since none of the participants scored at the lowest level of knowledge. Presence of ceiling/floor effects can influence important measurement properties, such as sensitivity and responsiveness³⁰.

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

The 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 variance explained by the main component was only 24.6% with a 7.49 eigenvalue, suggesting the existence of more than one dimension, which compromises unidimensionality^{22-24,26,29}. However, this division is consistent with the original version of the questionnaire, which has two dimensions, related to knowledge of the treatment and self-care. Subsequent analysis revealed that the two dimensions did not work as independent sub-scales, because when analyzed separately there was a reduction in the separation indices, reliability, and internal consistency. Therefore, it seems that the measurement of separated dimensions would not be justified.

When performing initial psychometric evaluation of the KDM-CF-Adolescent with 133 individuals with CF, Bernstein et al. (2018)¹⁵ also found the existence of two dimensions, given by exploratory factor analysis, self-care and knowledge of the disease sub-scales. Internal consistency for the self-care sub-scale was 0.74, while for the knowledge was 0.68 with a total calculated measure of 0.78. Reliability for the self-care subscale was 0.73 and for knowledge was 0.65 and the total measure was 0.76.

According to the established criterion ($r > 0.7$), none of the items showed local dependency, i.e., no item duplicated the content of another or the response to one item did not interfere with that of another. Question 13 (Food that contain the highest number of energy/calories are) was considered the most difficult and question 18 (With Cystic Fibrosis, cough) was 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 the time of application (15 to 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 found that the most frequent doubts that CF patients have are related to diet, both because of the discomfort of ingesting enzymes before every meal, and the lack of knowledge regarding the influence of medication on food absorption, acting on pancreatic and intestinal insufficiency. Another neglected point is the relationship between the disease and pulmonary function^{2-4,28}.

Kazmerski et al. (2015)³⁰ followed-up 38 adolescents (13 to 22 years) for two years. They observed that only

eight individuals used nutritional supplementation and six were at nutritional risk with body mass index (BMI) of 33. Although this study did not get information 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 contain greater amount of energy/calories are). Regarding the questions related to respiratory care, the sample had better knowledge but ignored the order they should follow to perform their care, since 57% of the patients missed the answer to question 15 "Time is everything; what is the right order to do the following treatments?" which addresses this issue. These findings should serve as a warning to the multidisciplinary team to increase educational actions related to nutrition and respiratory interventions.

This study has limitations. First, the fact that it was performed with a small sample and only with patients registered in AMAM may not reflect the national reality. Second, due to the COVID-19 pandemic and social isolation, 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 completed high school. Moreover, adherence of individuals to the treatment could not be approached. Third, the results 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 the development of a multicenter project involving adolescents with CF from all over the country to continue the KDM-CF-adolescent-Brazil validation process.

In summary, cross-cultural adaptation of the KDM-CF-Adolescent questionnaire for 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, considering the high percentage of errors in questions related to nutrition and respiratory issues. The results suggest that the KDM-CF-Adolescent-Brazil questionnaire could be used within clinical and research contexts, to measure the knowledge that adolescents with CF have about the disease. Future studies are needed to apply the questionnaire in a larger CF population to access other important measurement properties.

DATA AVAILABILITY

The entire dataset supporting the results of this study is available within the article.

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