



DEVELOPMENT AND VALIDATION OF QUALITY OF LIFE SCALE FOR PEOPLE LIVING WITH HIV

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ABSTRACT

Objective: to develop and validate a scale to measure the quality of life of people living with HIV in Brazil. **Method:** methodological study conducted in a Brazilian care service specialized in sexually transmissible infections/AIDS between 2017 and 2019 addressing people living with HIV. The scale's development and validation included exploratory factor analysis to describe its factor structure and psychometric properties, Multitrait-Multimethod analysis to verify its validity and Cronbach's alpha for reliability. Floor and ceiling effects were described according to the responses' frequency distribution.

Results: a total of 460 people living with HIV participated. Most were men 276 (60.0%) aged 43 on average (SD=±12.4). The Exploratory Factor Analysis revealed four factors with 39.9% of explained variance. The total scale presented satisfactory reliability with a Cronbach's alpha equal to 85.0%. Most items presented satisfactory convergent and divergent validity. The presence of floor and ceiling effects were found. The scale's final version was composed of 45 items.

Conclusion: the Quali-HIV Scale is a valid and reliable tool to measure the quality of life of people living with HIV.

DESCRIPTORS: HIV. Quality of life. Surveys and questionnaires. Validation studies. Psychometrics. Weights and measures. Chronic disease. Antiretroviral therapy, highly active.

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ELABORAÇÃO E VALIDAÇÃO DA ESCALA DE QUALIDADE DE VIDA DE PESSOAS VIVENDO COM HIV

RESUMO

Objetivo: elaborar e validar uma escala para mensurar a qualidade de vida de pessoas vivendo com HIV no Brasil.

Método: pesquisa metodológica realizada em um serviço brasileiro de atenção especializada em infecção sexualmente transmissível/Aids, entre 2017 e 2019, e que contemplou a participação de pessoas vivendo com HIV. O processo de elaboração e validação da escala compreendeu a descrição da estrutura fatorial, por meio da análise fatorial exploratória e propriedades psicométricas, segundo a análise Multitraço Multimétodo para validade, e Alfa de Cronbach para fidedignidade. Efeitos *floor* e *ceiling* foram descritos segundo distribuição de frequências das respostas.

Resultados: participaram 460 pessoas que vivem com HIV. A maioria dos participantes é do sexo masculino 276 (60,0%) e a média de idade foi 43 anos (DP=±12,4). Na Análise Fatorial Exploratória foram extraídos quatro fatores com variância explicada de 39,9%. A fidedignidade da escala total foi satisfatória com Alfa de Cronbach igual a 85,0%. A maioria dos itens apresentou validades convergente e divergente satisfatórias. Observou-se a presença dos efeitos *floor* e *ceiling* nas respostas. A versão final da escala foi composta por 45 itens.

Conclusão: a Escala Quali-HIV pode ser considerada uma ferramenta válida e fidedigna para mensurar a qualidade de vida de pessoas que vivem com HIV.

DESCRITORES: HIV. Qualidade de vida. Inquéritos e questionários. Estudos de validação. Psicometria. Pesos e medidas. Doença crônica. Terapia antirretroviral de alta atividade.

ELABORACIÓN Y VALIDACIÓN DE LA ESCALA DE CALIDAD DE VIDA DE PERSONAS VIVIENDO CON SIDA

RESUMEN

Objetivo: elaborar y validar una escala para medir la calidad de vida de personas viviendo con SIDA en Brasil. **Método:** investigación metodológica realizada en un servicio brasileño de atención especializada en infección sexualmente transmisible/SIDA, entre 2017 y 2019, y que contempló la participación de personas viviendo con SIDA. El proceso de elaboración y validación de la escala comprendió a descripción de la estructura factorial, por medio del análisis factorial exploratorio y propiedades psicométricas, según el análisis Multicaracterística Multi-método para validez, y Alfa de Cronbach para confiabilidad. Efectos *floor* y *ceiling* fueron descritos según distribución de frecuencias de las respuestas.

Resultados: participaron 460 personas que viven con SIDA. La mayoría de los participantes era del sexo masculino 276 (60,0%) y la media de edades fue 43 años (DE=±12,4). En el Análisis Factorial Exploratorio fueron extraídos cuatro factores con variancia explicada de 39,9%. La confiabilidad de la escala total fue satisfactoria con Alfa de Cronbach igual a 85,0%. La mayoría de los ítems presentó validez convergente y divergente satisfactoria. Se observó la presencia de los efectos *floor* y *ceiling* en las respuestas. La versión final de la escala estuvo compuesta por 45 ítems.

Conclusión: la Escala Quali-SIDA puede ser considerada una herramienta válida y fidedigna para mensurar a calidad de vida de personas que viven con SIDA.

DESCRIPTORES: SIDA. Calidad de vida. Encuestas y cuestionarios. Estudios de validación. Psicometría. Pesos y medidas. Enfermedad crónica. Terapia antirretroviral altamente activa.

INTRODUCTION

By the end of 2019, 38 million people lived with the Human Immunodeficiency Virus (HIV) worldwide¹. HIV is considered a debilitating, transmissible chronic disease, which under immunosuppressive conditions, allows the emergence of opportunistic infections that worsen an individual's clinical conditions².

Because it is a chronic disease, after the antiretroviral therapy (ART) is implemented, people living with HIV experience changes in their quality of life (QoL), possibly compromising aspects such as life satisfaction and HIV mastery, treatment adherence, in addition to increased concern with financial issues and health³. According to the World Health Organization, the concept of QoL is "an individual's 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^{4:1405}."

QoL is a multidimensional and subjective concept that includes parameters such as well-being, self-care with health and diet, and how satisfied people are with their living conditions⁴. The QoL construct among people living with HIV (PLHIV) is strongly linked to their health conditions⁵.

Tools intended to measure QoL are supposed to include efficacy and efficiency indicators and indicators measuring the impact of treatments on patients to support comparisons of procedures and dimension both costs and benefits. Therefore, the results found here will support the implementation of health actions intended to improve this population's QoL^{3–6}.

Given a growing concern with QoL and a search for instruments to measure it, the World Health Organization conducted a multicenter project called The World Health Organization Quality of Life Project to develop a QoL measure composed of 100 items⁴, the WHOQOL-100.

A measure intended to address specific issues concerning HIV emerged from this generic instrument; that is, a specific module was developed to assess the QoL among PLHIV, the so-called "WHOQOL-HIV"⁷. The psychometric properties of this scale's Brazilian version were tested and showed satisfactory reliability and concurrent validity⁸.

Another instrument widely used in Brazil is HAT-QoL. It comprises 34 items distributed into nine domains addressing overall function, life satisfaction, health worries, financial worries, medication concerns, HIV mastery, disclosure worries, provider trust, and sexual function. Its version in Portuguese was also validated in Brazil, presenting satisfactory reliability and validity⁹.

Despite the existence of these scales³⁻⁴, this study updates this construct considering impacts influencing this epidemic over 50 years. The Quali-HIV considers current needs and the dynamic nature of this epidemic, in addition to new epidemiological and social aspects. Thus, this study's objective was to develop and validate a scale to measure QoL among individuals living with HIV in Brazil.

METHOD

This methodological study based on the Psychometric Theory¹⁰ was conducted between 2017 and 2019 in a Specialized Care Service for Sexually Transmitted Infections (STIs)/AIDS located in a city in the interior of São Paulo, Brazil.

Rigor is required for each of the stages concerning the development of an instrument, in which systematic and standardized methods are used to obtain a reliable measure^{10–11}.

The process of establishing the first set of items to compose the Quali-HIV scale was guided by an integrative literature review and interviews held with this population. An initial version composed of 148 items emerged from this process. An expert committee composed of two experts in the topic,

two experts in the method, and one individual representing this population, verified its face and content validity. A 76-item instrument resulted from this stage, which was then submitted to semantic validation and a pre-test, from which the 51-item version used in this study emerged^{12–13}.

This study proceeded with the scale's validation addressing a population composed of PLHIV in follow-up at a health service. Individuals of both sexes, aged 18 old or older, with an HIV diagnosis for at least six months and taking the antiretroviral therapy for at least three months participated in the study. The guidelines provided by the Ministry of Health concerning the ART protocol were considered to include the participants. According to this protocol, all PLHIV, regardless of their viral load, should take antiretroviral therapy¹⁴. Imprisoned and institutionalized individuals were excluded.

The sample size was determined according to the literature¹⁵, and a convenient sample was selected. The individuals were invited to participate in the study while they awaited their scheduled medical appointments. A previously validated instrument in terms of form and content, addressing the individuals' sociodemographic and clinical aspects and lifestyle, was used to interview and characterize the participants.

The participants rated the first set of items composing the self-reported Quali-HIV on a five-point Likert scale.

The scale's development and validation included a description of its factor structure, reliability, convergent and divergent construct validity, in addition to floor and ceiling effects.

An Exploratory Factor Analysis was performed to describe the scale's factor structure concerning the number of factors and allocation of items in each factor. The Kaiser-Meyer-Olkin (KMO) test and Bartlett's sphericity test were performed to verify whether the data matrix could be factorized¹⁶.

The unweighted least squares method and Varimax rotation were used in the extraction of the factors. Factor loadings below 0.30 were the criterion used to exclude items¹¹. A scree plot helped to determine the number of factors¹⁵.

In this study, reliability was verified using Cronbach's alpha coefficient. Therefore, the items' internal consistency and dimensions were verified. Coefficients can range between 0 and 1, whereas 0 indicates lack of internal consistency and 1 represents total internal consistency;¹¹ values above 0.7 were considered acceptable¹⁷.

The Multitrait-Multimethod analysis was used to describe convergent and divergent construct validity. Acceptable product-moment correlation coefficients, between an item and the factor to which it belongs, are supposed to be higher than 0.40 to confirm convergent validity. Divergent validity is verified through the percentage of times in which product-moment correlation coefficients, between an item and the factor to which it belongs, are higher or statistically higher than those between the item and the factors it does not belong. The closer to 100, the more discriminant the dimensions are (goodness of fit)¹¹.

Floor and ceiling effects occur when the scores are not symmetrically distributed, and more than 15% of the responses are concentrated either on the minimum or maximum scores of a scale, respectively. The occurrence of these effects reduces a scale's responsiveness, preventing or hindering verifying whether the construct changed in situations in which one's health condition worsened or improved^{17–18}.

IBM® SPSS version 20.0 was used to determine the factor structure and reliability, and the Multitrait Analysis Program (MAP) was used to perform the Multitrait-Multimethod analysis and verify the correlations between the items and their respective factors^{11,19}.

This study complied with all the ethical guidelines recommended by Resolution 466/12 and the participants signed free and informed consent forms.

RESULTS

A total of 460 PLHIV participated in this study, and the information concerning 367 participants was used to describe the scale's factor structure and remaining psychometric properties.

The participants were 43 years old on average (SD=±12.4), ranging from 18 to 73. Most were men 276 (60.0%), heterosexual 313 (68.0%), single 226 (49.1%), and completed high school 182 (39.6%). The participants' laboratory characteristics concerning HIV infection and clinical characteristics are presented in Table 1.

Table 1 – Laboratory and clinical characteristics of the participants answering the Quali-HIV. Ribeirão Preto, SP, Brazil, 2017-2019. (n=460)

Variables		Т	otal
Variables	-	N	%
	< 2	105	22.8
How long the individual was aware	2 to5	64	13.9
of the HIV infection (years)	> 5	291	63.3
	≤ 350	54	11.7
TCD4+ lymphocytes (mm³/blood)	351 to 500	85	18.5
	>500	321	69.8
	Undetectable (≤ 40)	397	86.3
Vivel 1 d (i (1)	<10,000	37	8.1
Viral load (copies/ml)	10,000 to 100,000	19	4.1
	>100,000	07	1.5
	No comorbidities	273	59.3
Comorbidities	One comorbidity	115	25.0
Comorbidities	Two or more comorbidities	72	15.7
On infantian	No co-infection	402	87.4
Co-infection	Co-infection	58	12.6

The Quali-HIV Scale composed of 51 items was used in the factor structure analysis. The correlation matrix showed satisfactory covariance (0.832) for factor extraction through the KMO test, and Bartlett's sphericity test presented a significant result (<0.001).

The Scree Plot showed eigenvalues equal to or higher than 1, showing the scale possibly had four factors. To compose the factors and considering the criterion of explained variance, the distribution and arrangement of items revealed a model composed of 51 items distributed into four factors. This was the most appropriate outcome, with an explained variance of 36.45% (Table 2).

Table 2 – Explained variance of the Quali-HIV factors according to the first Exploratory Factor Analysis. Ribeirão Preto, SP, Brazil, 2017-2019. (n=357)

	Total variance explained										
F	Initia	al eigenval	ues	Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings				
	Total	%*	%†	Total	%*	%†	Total	%*	%†		
1	8.76	17.17	17.17	8.76	17.17	17.17	6.86	13.46	13.46		
2	4.56	8.93	26.11	4.56	8.93	26.11	3.06	6.01	19.46		
3	3.03	5.93	32.04	3.03	5.93	32.04	2.66	5.22	24.68		
4	2.25	4.42	36.46	2.25	4.42	36.46	2.52	4.93	29.61		
5	1.88	3.70	40.15	1.88	3.70	40.15	2.28	4.48	34.09		
6	1.60	3.14	43.30	1.60	3.14	43.30	2.18	4.27	38.36		
7	1.50	2.94	46.23	1.50	2.94	46.23	1.96	3.85	42.21		
8	1.46	2.87	49.11	1.46	2.87	49.11	1.63	3.19	45.40		
9	1.38	2.72	51.82	1.38	2.72	51.82	1.59	3.13	48.52		
10	1.33	2.60	54.42	1.33	2.60	54.42	1.59	3.11	51.63		
_	_	_	_	_	_	_	_	_	_		
51	0.18	0.35	100.00								

F=Number of factors.*= percentage of variance;†= cumulative percentage.

Six items were excluded for not meeting the absolute value criterion: Q8-Tomo os antirretrovirais nos horários corretos [I take the antiretroviral medication at the right time]; Q9-Recebo informações da equipe de saúde sobre o meu tratamento [The health staff provides information about my treatment]; Q10-Recebo informações da equipe de saúde sobre os efeitos adversos dos antirretrovirais [The health staff provides information regarding the antiretroviral adverse effects]; Q41-Minha família me julga culpado por ter contraído o HIV [My family blames me for having contracted HIV]; Q42-Recebo apoio da minha família por viver com HIV [My family supports me for living with HIV]; Q45-O HIV pode interferir na capacidade de ter filhos [HIV may interfere in my ability to have children].

After excluding items 8,9,10,41,42, and 45, new exploratory factor analysis was performed with the number of factors that represented 39.96% of the explained variance, which resulted in a version with 45 items distributed into four factors (Table 3).

Table 3 – Factor matrix and communalities of the Quali-HIV scale (51 items). Ribeirão Preto, SP, Brazil, 2017-2019. (n=357)

Rotated Component Matrix								
Scale's items	Factors							
Scale's items	1	2	3	4				
Item 1		.673						
Item 3		.672						
Item 4		.381						
Item 5		.401						
Item 11		.437						
Item 12				.488				
Item 13	.453							
Item 14	.373	.360						
Item 15		.401						

Table 3 - Cont.

Rotate	ed Compo	nent Matri	ix				
Saala'a itama	Factors						
Scale's items	1	2	3	4			
Item 16		.342					
Item 17	.541						
Item 20		.482					
Item 21	.403	.334					
Item 23		.391					
Item 29	.388						
Item 32		.413					
Item 33		.469					
Item 37	.486	.373					
Item 46			.836				
Item 47			.814				
Item 48			.760				
Item 50	.382						
Item 51				.534			
Item 2*R	.621						
Item 6*R	.326						
Item 7*R	.320						
Item 18*R	.648						
Item 19*R				.411			
Item 22*R	.464						
Item 24*R	.381	324		.495			
Item 25*R	.619						
Item 26*R	.478	426					
Item 27*R				.565			
Item 28*R	.713						
Item 30*R	.678						
Item 31*R	.330						
Item 34*R	.304						
Item 35*R	.440						
Item 36*R	.746						
Item 38*R	.463	323					
Item 39*R	.522						
Item 40*R	.540						
Item 43*R	.741						
Item 44*R	.631						
Item 49*R	.622						
Eigenvalues	8.54	4.42	2.93	2.09			
Variance explained (%)	18.98	28.79	35.30	39.95			
Cronbach's alpha	0.90	0.75	0.86	0.70			

Extraction method: Unweighted least squares. Rotation method: Varimax with Kaiser's method. a. Rotation converged in 6 iterations. *R: Inverted items.



The Quali-HIV's reliability was verified with a Cronbach's alpha equal to 0.85. The factors' coefficients ranged from 0.68 and 0.89. The four rotated factors were distributed as follow: Factor 1 was composed of 16 items with a Cronbach's alpha equal to 0.89; Factor 2 grouped 11 items, with Cronbach's alpha equal to 0.75; Factor 3 comprised three items with a Cronbach's alpha equal to 0.85, and Factor 4 was composed of 5 items with a Cronbach's alpha equal to 0.68.

Regarding convergent validity, Table 4 presents the product-moment correlations that resulted from the MAP analysis. Most items (93.3%) presented satisfactory values, above 0.40.

Table 4 – Pearson's correlation coefficient between the items and factors of the Quali-HIV Scale. Ribeirão Preto. SP. Brazil. 2017-2019. (n=103)

		Standard	Factor						
Item	Mean	deviation	F1	F2	F3	F4	Total		
Item 13	3.64	1.34	0.16	0.23	0.01	0.01	0.23		
Item 14	4.04	1.17	0.31	0.25	-0.05	0.11	0.39		
Item 17	4.52	0.98	0.46	0.01	0.20	0.11	0.45		
Item 21	3.75	1.08	0.55	0.9	0.8	0.32	0.59		
Item 29	2.86	1.37	0.34	0.01	-0.01	0.26	0.36		
Item 37	3.85	1.11	0.47	0.22	0.07	0.13	0.53		
Item 50	3.41	1.32	0.22	0.16	-0.04	-0.08	0.23		
Item 02	4.50	1.00	0.51	0.07	0.05	0.18	0.51		
Item 06	4.43	1.16	0.54	-0.16	0.20	0.18	0.46		
Item 07	4.62	0.83	0.47	-0.03	0.18	0.20	0.46		
Item 18	4.10	1.39	0.57	-0.24	0.26	0.24	0.48		
Item 22	4.37	1.08	0.55	-0.29	0.00	0.24	0.41		
Item 25	4.34	1.14	0.62	-0.08	0.4	0.34	0.58		
Item 26	3.53	1.41	0.48	-0.37	0.08	0.34	0.35		
Item 28	4.52	0.93	0.69	-0.01	0.01	0.20	0.63		
Item 30	4.01	1.26	0.71	-0.16	0.06	0.28	0.60		
Item 31	3.60	1.48	0.41	-0.25	-0.06	0.30	0.32		
Item 34	3.80	1.45	0.40	-0.23	-0.10	0.39	0.33		
Item 35	4.04	1.27	0.46	-0.04	0.12	0.07	0.41		
Item 36	4.32	1.14	0.76	-0.17	0.10	0.34	0.66		
Item 38	3.85	1.42	0.52	-0.26	0.23	0.18	0.41		
Item 39	4.02	1.34	0.59	-0.20	0.26	0.24	0.50		
Item 40	4.38	1.12	0.45	0.08	0.14	0.03	0.44		
Item 43	4.21	1.13	0.73	-0.11	0.15	0.27	0.66		
Item 44	4.55	0.99	0.46	-0.15	0.13	0.34	0.43		
Item 49	3.15	1.37	0.64	-0.02	0.05	0.34	0.62		
Item 01	3.56	1.38	0.08	0.56	-0.10	-0.09	0.23		
Item 03	3.58	1.35	-0.01	0.62	-0.20	-0.06	0.16		
Item 04	2.15	1.41	-0.05	0.37	-0.20	0.05	0.07		
Item 05	4.72	0.67	0.17	0.12	0.07	0.03	0.21		
Item 11	2.60	1.53	0.10	0.46	0.03	-0.05	0.24		
Item 15	4.79	0.43	-0.15	0.47	-0.18	-0.22	-0.03		
Item 16	4.57	0.89	-0.05	0.19	-0.05	-0.01	0.02		

Table 4 - Cont.

Itam	Maan	Standarddeviation			- Total		
Item	Mean		F1	F2	F3	F4	TOTAL
Item 20	2.95	1.24	0.00	0.56	0.03	0.07	0.21
Item 23	3.14	1.39	-0.30	0.44	-0.02	-0.17	-0.15
Item 33	3.03	1.48	-0.15	0.35	-0.06	-0.07	-0.03
Item 32	3.44	1.47	-0.34	0.45	-0.15	-0.14	-0.19
Item 46	4.64	0.68	0.25	-0.04	0.70	-0.10	0.24
Item 47	4.39	1.09	0.06	-0.11	0.59	-0.09	0.03
Item 48	4.63	0.75	0.09	-0.19	0.60	-0.08	0.04
Item 12	1.87	1.23	0.18	0.17	-0.18	0.46	0.28
Item 51	2.37	1.19	0.24	-0.09	0.04	0.46	0.27
Item 19	4.05	1.32	0.12	0.13	-0.16	0.04	0.15
Item 24	3.43	1.56	0.43	-0.26	0.02	0.46	0.37
Item 27	3.02	1.43	0.25	-0.22	-0.08	0.62	0.23

Note: Featured – Pearson's Correlation Coefficient of item in relation to factor.

According to MAP, convergent validity also presented satisfactory results as the scale as a whole presented goodness of fit equal to 96.3%. When the factors were analyzed separately, Factors 1 and 2 presented 98.7% and 97.0% respectively; Factor 3 presented goodness of fit of 100% and Factor 4 presented goodness of fit of 80% (Table 5).

Table 5 – Result of the MAP analysis for the factors in the Quali-HIV Scale. Ribeirão Preto, SP, Brazil, 2017-2019. (n=103)

	Factors									
	F1		F2		- 1	F3		- 4	Total	
	N	%	N	%	N	%	N	%	N	%
-2	00	0	0	0	00	0	00	0	00	0
-1	01	1.3	1	3.0	00	0	03	20.0	05	3.7
1	14	17.9	8	24.2	00	0	01	6.7	23	17.0
2	63	80.8	24	72.7	09	100.0	11	73.3	107	79.3
1+2	77	98.7	32	97.0	09	100.0	12	80.0	130	96.3
Goodness of fit		100%								

Of 45 items resulting from the exploratory factor analysis, floor and ceiling effects occurred in 29 and 16 items, respectively.

DISCUSSION

Quality of life among PLHIV is a relevant topic in the historical context of the disease, considering that improved knowledge concerning diagnosis and its treatment has impacted how the infection is managed and how people live with it²⁰.

The individuals participating in the development and validation of the Quali-HIV Scale were PLHIV, most of whom were men. Even though the infection profile changed in recent years, such as the feminization of HIV, predominantly male individuals become infected. Data presented in this study corroborate the epidemiological bulletin issued in 2018 by the *Secretaria de Vigilância em Saúde*

[Health Surveillance Department]. The ratio between sexes for HIV diagnosis was 26 men for every ten women diagnosed with the disease, without considering infections among pregnant women²¹. Data reported between 2007 to June 2019 revealed 300,496 HIV infections in Brazil,136,902 (45.6%) of which were identified in the southeast. The rate of detection according to sex may vary according to the region; however, a predominance of cases among men was found in most regions; a finding also reported by other studies^{3,22–24}.

This study shows a prevalence of heterosexual men; however, most men exposed to the virus in the southeast and mid-west reported to be gay or bisexual²¹.

Factor analysis was applied to verify the instrument's structural construct, establishing the factors and the relationship between the variables¹⁵. Factor analysis is a tool used to explore the dimensions of a scale. In this study, this analysis enabled identifying four factors: Factor 1 (26 items), Factor 2 (11 items), Factor 3 (3 items), and Factor 4 (5 items). Therefore, the final instrument was composed of 45 items.

Note that Factor 1, called "Impact of HIV infection on QoL," addresses items concerning daily activities, the treatment, diagnosis, and friendships. Factor 2 "Well being" comprises items concerning leisure, the use of antiretroviral therapy, diet, and religion, among others. Factor 3 "Physical Activity," includes items that concern exercise, and Factor 4 "HIV diagnosis," includes items concerning serological status, confidentiality, fears, and difficulties. These factors represented 40.0% of the construct's explained variance.

The factors included in the Quali-HIV Scale reflect aspects that are essential to assess QoL, considering it is a multidimensional construct^{4,11}.

Factor analysis is widely used by studies developing and validating scales to assess construct validity because it enables identifying factors that explain the construct under study. Construct validity is the most important psychometric assessment for a measurement tool¹¹.

The instrument's construct validity was verified using convergent and divergent validity of the Quali-HIV Scale; both were performed using MAP^{11–15}.

The results obtained for the Quali-HIV Scale showed satisfactory convergent validity for most items (42 items) and their respective factors, with a satisfactory correlation between them¹¹. Corroborating this study's findings, one study recommends similar correlations for this validity²⁵. Only three items presented small correlations with their factors. However, after a qualitative analysis, we decided to keep the factors where they were allocated.

Note that a high proportion of common variance in convergent validity is supposed to be contained in the items indicating a specific construct¹⁵.

Regarding discriminant validity, it shows the degree in which a construct diverge from the remaining¹⁵. In this study, the instrument presented satisfactory goodness of fit. It can be verified considering the percentage of items that present higher correlations with their respective factors than with the remaining factors¹¹. The high percentages of factors and of the scale as a whole confirmed the instrument's validity.

Validating or adapting a specific instrument to measure health-related QoL ensures that the participants access the same construct²⁶.

Regarding the Quali-HIV reliability, satisfactory indexes were found for the total scale and each of its factors¹⁷. A similar result was reported by a study that used this instrument to assess the QoL of PLHIV²⁷. Additionally, the investigation developed to assess the psychometric properties of the WHOQOL-HIV Bref obtained a Cronbach's alpha equal to 0.93²⁸.

The description of floor and ceiling effects is based on the answers provided to the instrument, considering that the participants may opt for one extreme or the other. This dynamic may compromise

the variability of responses. Respondents may use this strategy for finding it difficult to rate their experiences²⁹, and these effects may influence the instrument's responsiveness and reliability¹⁷.

Positive and negative terms included in the items may result in these effects³⁰. Other studies validating instruments measuring health-related QoL also identified these effects²⁹. Nonetheless, it is worth noting that these effects may be related to the perception of QoL held by PLHIV.

After the development and validation processes, the conclusion is that the Quali-HIV Scale is a valid and reliable instrument to measure QoL among PLHIV.

This study's limitation refers to the fact that the development and validation of this scale were conducted in the population assisted by Specialized Care Units IST/HIV located in a single Brazilian city.

CONCLUSION

This study's relevance lies on the fact that there is a lack of updated tools to measure QoL among PVHIV and this study provides a valid and reliable instrument to be used by nursing workers and other professionals providing individualized care to this population.

The Quali-HIV scale was developed in Brazil, considering the current context of the HIV epidemic. Its importance is linked to the methodological rigor applied during its development. Thus, the Quali-HIV scale is an updated instrument that can be replicated and used to diagnose the QoL of individuals living with HIV to support health care actions implemented to this population.

This scale can be used in various settings and adapted to other contexts. However, its use has to be authorized by the primary author, considering that the studies addressing this scale will contribute to improved knowledge.

REFERENCES

- 1. World Health Organization. Number of people (all ages) living with HIV. Estimates by WHO region. [Internet]. Geneva(CH): WHO; 2020 [cited 2021 Jan 21]. Available from: https://apps.who.int/gho/data/node.main.620?lang=en
- 2. Castro JM, Ribeiro ECPS, Souza JFS. Assistência enfermagem a paciente portador da síndrome da imunodeficiência adquirida: um relato de caso. Braz J Surg Clin Res [Internet]. 2017 [cited 2020 Apr 07];20(1):88-90. Available from: https://www.mastereditora.com.br/periodico/20170905 173745.pdf
- 3. Primeira MR, Santos WM, Paula CC, Padoin SMM. Quality of life, adherence and clinical indicators among people living with HIV. Acta Paul Enferm.[Internet]. 2020 [cited 2021 Jan 20];33:eAPE20190141. Available from: https://doi.org/10.37689/acta-ape/2020ao0141
- 4. World Health Organization. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. Soc Sci Med. 1995 [cited 2020 Apr 07];41(10):1403-9. Available from: https://doi.org/10.1016/0277-9536(95)00112-k
- 5. Domingues JP, Oliveira DC, Marques SC. Quality of life social representations of people living with hiv/aids. Texto Contexto Enferm. [Internet]. 2018 [cited 2021 Feb 02];27(2):e1460017. Available from: https://doi.org/10.1590/0104-070720180001460017.
- Moraes RYT, Rocha CJ, Bushatsky M, Silva RA, da Silva Filho JC, Célia OR. Self-evaluating the quality of life of people living with HIV. Cienc Cuid Saúde [Internet]. 2019 [cited 2020 Apr 07];18(2):e47022. Available from: https://doi.org/10.4025/cienccuidsaude.v18i2.47022
- 7. World Health Organization. Initial steps to developing the World Health Organization's Quality of Life Instrument (WHOQOL) module for international assessment in HIV/AIDS. AIDS Care [Internet]. 2003 [cited 2020 Apr 07];15(3):347-57. Available from: https://doi.org/10.1080/0954012031000105405
- 8. Zimpel RR, Fleck MP. Quality of life in HIV-positive Brazilians: application and validation of the WHOQOL-HIV, Brazilian version. AIDS Care [Internet]. 2007 [cited 2020 Apr 07];19(7):923-30. Available from: https://doi.org/10.1080/09540120701213765

- de Soárez PC, Castelo A, Abrão P, Holmes WC, Ciconelli RM. Tradução e validação de um questionário de avaliação da qualidade de vida em AIDS no Brasil. Rev Panam Salud Pública [Internet]. 2009 [cited 2020 Apr 07];25:69-76. Available from: https://www.scielosp.org/pdf/ rpsp/2009.v25n1/69-76
- 10. Pasquali, L. Psychometrics. Rev Esc Enferm USP [Internet]. 2009 [cited 2020 Apr 07];43(Spe):992-9. Available from: https://doi.org/10.1590/S0080-62342009000500002
- 11. Fayers PM, Machin D. Quality of life: Assessment. The assessment, analysis, and interpretation of patient-reported outcomes. 2nd ed. Chichester (UK): John Wiley & Sons; 2007
- Castrighini CC. Elaboração de escala para avaliação da qualidade de vida de pessoas vivendo com HIV/aids [tese]. Ribeirão Preto, SP(BR): Escola de Enfermagem de Ribeirão Preto da USP; 2017.
- Almeida-Cruz MCM, Castrighini CC, Sousa LRM, Pereira-Caldeira NMV, Reis RK, Gir E. Percepções acerca da qualidade de vida de pessoas vivendo com HIV. Esc. Anna Nery [Internet]. 2021 [cited 2021 Jan 22];25(2):e20200129. Available from: https://doi.org/10.1590/2177-9465-ean-2020-0129.
- 14. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância, Prevenção e Controle das Infecções Sexualmente Transmissíveis, do HIV/Aids e das Hepatites Virais. Clinical Protocol and Therapeutic Guidelines for the Management of HIV Infection in Adults. Brasília, DF(BR): Ministério da Saúde [Internet]. 2018 [cited 2021 Jan 22]. Avaliable from: http://www.aids.gov.br/pt-br/pub/2013/protocolo-clinico-e-diretrizes-terapeuticas-para-manejo-da-infeccao-pelo-hiv-em-adultos
- 15. Hair Junior JF, Black WC, Babin BJ, Anderson RE, Tathan RL. Análise multivariada de dados. 6th ed. Porto Alegre, RS(BR): Bookman; 2009.
- Dziuban CD, Shirkey EC. On the psychometric assessment of correlation matrixes. Am Educ Res J [Internet]. 1974 [cited 2020 Apr 07];11(2):211-6. Available from: https://doi.org/10.2307/1161796
- 17. Terwee CB, Bot SDM, de Boer MR, van der Windt DAWM, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol [Internet]. 2007 [cited 2020 Apr 07];60(1):34-42. Available from: https://doi.org/10.1016/j.jclinepi.2006.03.012
- 18. McHorney CA, Tarlov AR. Individual-patient monitoring in clinical practice: are avaliable health status surveys adequate? Qual Life Res [Internet]. 1995 [cited 2020 Apr 07];4(4):293-307. Available from: https://doi.org/10.1007/BF01593882
- Hays RD, Hayashi T, Carson S, Ware JE. User's guide for the multitrait analysis program (MAP).
 Santa Monica, CA(US): RAND Corporation; 1988. [cited 2020 Apr 07]. Available from: https://www.rand.org/pubs/notes/N2786.html
- Petry S, Padilha MI, Maia AR, Gapski GB. Produção acadêmica da enfermagem acerca dos temas HIV e aids: um estudo histórico-social. Rev Enferm UFSM [Internet]. 2019 [cited 26 Jan 2021];9:e29: Avaliable from: https://doi.org/10.5902/2179769235114
- 21. Ministério da Saúde (BR), Secretaria de Vigilância em Saúde. Boletim Epidemiológico de HIV e AIDS. Número Especial. Brasília, DF(BR): Ministério da Saúde; 2019 [cited 2021 Jan 26]. Available from: https://antigo.saude.gov.br/images/pdf/2019/novembro/29/Boletim-Ist-Aids-2019-especial-web.pdf
- 22. Martins Neto C, Pires EMC, Brito CS, Beserra OLMG, Silva Junior JF, Mota JV, et al. Qualidade de vida no contexto de pacientes com HIV/AIDS: Um estudo comparativo. Saúde e Pesqui [Internet]. 2019 [cited 2020 Apr 07];12(2):333-41. Available from: https://doi.org/10.17765/2176-9206.2019v12n2p333-341



- 23. Costa VT, Meirelles BHS. Adherence to treatment of young adults living with hiv/aids from the perspective of complex thinking. Texto Contexto Enferm [Internet]. 2019 [cited 2020 Aug 26];28:e20170016. Available from: https://doi.org/10.1590/1980-265x-tce-2017-0016
- 24. Gomes AMT. Representações sociais da espiritualidade de quem vive com Aids: um estudo a partir da abordagem estrutural. Psicol Soc [Internet]. 2016 [cited 2020 Apr 07];5(2):187-97. Available from: https://doi.org/10.12957/psi.saber.soc.2016.27037
- 25. Cohen J. Statistical power analysis for the behavioral sciences. 2nd ed. New York (US): Hillsdale: Lawrence Elrbaum Associates; 1988.
- 26. Santos DMSS, Deon KC, Bullinger M, Santos CB. Validity of the DISABKIDS® Cystic Fibrosis Module for Brazilian children and adolescents. Rev Latino-Am Enfermagem [Internet]. 2014 [cited 2020 Apr 07];22(5):819-25. Available from: https://doi.org/10.1590/0104-1169.3450.2485
- Barbosa KSS, Castro SS, Leite CF, Nacci FR, Accioly MF. Validation of the Brazilian version of the World Health Organization Disability Assessment Schedule 2.0 for individuals with HIV/ AIDS. Ciênc Saúde Coletiva [Internet]. 2020 [cited 2020 Apr 07];25(3):837-44. Available from: https://doi.org/10.1590/1413-81232020253.18992018
- 28. Silveira MF, Ferreira AC, Brito MFSF, Pinho L, Teixeira Júnior AL, Carneiro M. Propriedades psicométricas do WHOQOL-HIV Bref para avaliação da qualidade de vida. Psico-USF [Internet]. 2019 [cited 2020 Apr 07];24(3):475-87. Available from: https://doi.org/10.1590/1413-82712019240306
- 29. Santos DMSS, Deon KC, Fegadolli C, Reis RA, Torres LAGMM, Bullinger MS, et al. Cultural adaptation and initial psychometric properties of the DISABKIDS® Cystic Fibrosis Module Brazilian version. Rev Esc Enferm USP [Internet]. 2013 [cited 2020 Apr 07];47(6):1311-7. Available from: https://doi.org/10.1590/S0080-623420130000600009
- 30. Chan KS, Mangione-Smith R, Burwinkle TM, Rosen M, Varni JW. The PedsQL: reliability and validity of the short-form generic core scales and Asthma Module. Med Care [Internet]. 2005 [cited 2020 Apr 07];43(3):256-65. Available from: https://doi.org/10.1097/00005650-200503000-00008

NOTES

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CONFLICT OF INTEREST

There is no conflict of interest.

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