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VALIDATION OF *INSTRUMENTO DE EVALUACIÓN DE LA EXPERIENCIA DEL PACIENTE CRÓNICO* FOR BRAZILIAN PORTUGUESE

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ABSTRACT

Objective: to analyze the metric properties of the *Instrumento de Evaluación de la Experiencia del Paciente Crónico* version adapted to Brazilian Portuguese.
Method: this is a methodological and cross-sectional study conducted with 132 patients with chronic kidney disease on hemodialysis. *Cronbach*'s alpha was used in the reliability assessment. Construct validity was assessed by means of Exploratory Factor Analysis and Confirmatory Factor Analysis.
Results: the *Instrumento de Evaluación de la Experiencia del Paciente Crónico* tool obtained an overall *Cronbach*'s alpha of 0.75. Unidimensionality of the instrument was recommended in the Exploratory Factor Analysis and confirmed through Confirmatory Factor Analysis, with the indices indicating good fits according to the established criteria. The results indicated the following values: $\chi^2/g = 1.129$; *Goodness-of-Fit Index* = 0.96; *Root-Mean-Square Error of Approximation* = 0.050; *Tucker-Lewis Index* = 0.97 and *Adjusted Goodness-of-Fit Index* = 0.94.
Conclusion: the *Instrumento de Evaluación de la Experiencia del Paciente Crónico* tool shows diverse evidence of satisfactory reliability and validity in patients with chronic kidney disease undergoing hemodialysis.

DESCRIPTORS: Validation studies. Methodological research in Nursing. Chronic renal failure. Patient-centered care. Nursing.

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VALIDAÇÃO DO *INSTRUMENTO DE EVALUACIÓN DE LA EXPERIENCIA DEL PACIENTE CRÓNICO* PARA O PORTUGUÊS DO BRASIL

RESUMO

Objetivo: analisar as propriedades métricas da versão adaptada do *Instrumento de Evaluación de la Experiencia del Paciente Crónico* para o português do Brasil.
Método: trata-se de um estudo metodológico e transversal, realizado com 132 pacientes com doença renal crônica que realizam hemodiálise. Na avaliação da confiabilidade, utilizou-se o alfa de *Cronbach*. A validade de construto foi avaliada por meio da análise fatorial exploratória e da análise fatorial confirmatória.
Resultados: o *Instrumento de Evaluación de la Experiencia del Paciente Crónico* obteve um alfa de *Cronbach* total de 0,75. A unidimesionalidade do instrumento foi recomendada na análise fatorial exploratória e ratificada por meio da análise fatorial confirmatória, com os índices indicando bons ajustes, de acordo com os critérios estabelecidos. Os resultados indicaram os seguintes valores: χ^2/g =1,129; *Godness-of-Fit Index* = 0,96; *Root-Mean-Square Error of Approximation*= 0,050; *Tucker-Lewis Index* =0,97 e *Adjusted Goodness-of-Fit Index* =0,94.
Conclusão: o *Instrumento de Evaluación de la Experiencia del Paciente Crónico* possui evidências de confiabilidade e validade satisfatórias em pacientes com doença renal crônica que realizam hemodiálise.

DESCRITORES: Estudos de validação. Pesquisa metodológica em enfermagem. Insuficiência renal crônica. Assistência centrada no paciente. Enfermagem.

VALIDACIÓN DEL *INSTRUMENTO DE EVALUACIÓN DE LA EXPERIENCIA DEL PACIENTE CRÓNICO* PARA PORTUGUÉS DE BRASIL

RESUMEN

Objetivo: analizar las propiedades métricas de la versión del *Instrumento de Evaluación de la Experiencia del Paciente Crónico* adaptada al portugués de Brasil.
Método: estudio metodológico y transversal realizado con 132 pacientes que padecen enfermedad renal crónica sometidos a hemodiálisis. Para evaluar la confiabilidad se utilizó el coeficiente alfa de *Cronbach*. La validez del constructo se evaluó por medio de Análisis Factorial Exploratorio y Análisis Factorial Confirmatorio.
Resultados: el *Instrumento de Evaluación de la Experiencia del Paciente Crónico* obtuvo un coeficiente alfa de *Cronbach* total de 0,75. El Análisis Factorial Exploratorio recomendó unidimesionalidad del instrumento, que fue ratificada por medio del Análisis Factorial Confirmatorio, con índices que indicaron buenos ajustes de acuerdo con los criterios establecidos. Los resultados indicaron los siguientes valores: χ^2/g = 1,129; *Goodness-of-Fit Index* = 0,96; *Root-Mean-Square Error of Approximation* = 0,050; *Tucker-Lewis Index* = 0,97 y *Adjusted Goodness-of-Fit Index* = 0,94.
Conclusión: el *Instrumento de Evaluación de la Experiencia del Paciente Crónico* presenta satisfactorias evidencias de confiabilidad y validez en pacientes con enfermedad renal crónica sometidos a hemodiálisis.

DESCRIPTORES: Estudios de validación. Investigación metodológica en Enfermería. Insuficiencia renal crónica. Asistencia centrada en el paciente. Enfermería.

INTRODUCTION

Chronic Non-Communicable Diseases (CNCDs) are characterized by a group of multifactorial-origin morbidities that lead to deaths, quality of life losses (with high limitation and inability degrees for activities of daily living), and significant economic burdens for society and governments[1], Among the main CNCDs are Systemic Arterial Hypertension (SAH) and Diabetes *Mellitus*, which, along with population aging and other health determinants, have influenced the increase in the number of individuals with Chronic Kidney Disease (CKD), considered the main morbidities associated with the development of renal dysfunctions[2–3].

CKD is characterized as an irreversible condition leading to a series of biochemical, clinical and metabolic changes, responsible for high hospitalization, morbidity and mortality rates[4]. Among the treatment possibilities for CKD, hemodialysis is the most widely employed therapy on a global scale. In countries such as China, South Africa, India, United States and Brazil, it is the main treatment modality for more than 80% of the patients[5].

Individuals with CKD undergoing hemodialysis face countless lifestyle changes due to the constraints imposed by the disease, the therapeutic requirements, clinical control and increased chances for frequent hospitalizations [6]. The hemodialysis treatment is invasive, requires specialized care, entails substantial economic costs and induces physical and psychosocial wear out on patients and their families[7]. In order to conduct this treatment, the patients generally attend a dialysis unit three times a week, which imposes on them varying degrees of interaction and contact frequency with health services and professionals[8].

Health care in hemodialysis should encompass self-care encouragement, infection prevention and provision of diverse information to the patient and family in relation to the treatment and complications, in addition to recommending a safe and comfortable environment to undergo this treatment[9]. These care measures should be implemented both within the health unit and in the home environment, guiding the patient to take on an active role and encouraging self-care[10].

In this perspective, at the *MacColl Institute for Health Innovation* in Seattle, United States, Wagner et al. developed the *Chronic Care Model* (CCM), which suggests a systemic transformation to provide proactive, planned, integrated and patient-centered care[11]. Drawing theoretically from the CCM, a team of professionals from several institutions in Spain (Regional Health Services, Health Research and Innovation Institutes, Universities and Companies) developed the "*Instrumento de Evaluación de la Experiencia del Paciente Crónico* (IEXPAC)" tool to assess the experience of individuals with chronic diseases in their interactions with health and social professionals and services[12].

The patients' experience is defined as the information provided by the individual regarding what happened in their ongoing interaction with health and social services and professionals, and how they perceived this interaction and its outcomes[12]. Through it, it is possible to assess how health and social assistance providers are organized to adequately meet the patients' needs[13].

Studies conducted with patients with chronic diseases evidence that providing good quality care significantly enhances the experience, with productive patient-professional interactions being important for the patients' well-being and for care quality[14–15].

In this context, it is observed that patients with CKD have a lot to say about their relationship with health and social services and professionals, as well as about the care they receive. Therefore, it is essential to know their experience to improve quality of the assistance provided and favor patient-centered care.

In Brazil, the use of instruments to assess the experience of patients with chronic diseases is still incipient[16]. The instruments do not encompass elements related to the evolution of information and communication technologies in chronic care and fail to directly assess the coordination between health and social assistance providers[12].

However, IEXPAC considers elements that were not addressed in other instruments. In its original version, it presented appropriate metric properties as measured by *Cronbach*'s alpha, the goodness-of-fit index, and convergent validity[12]. It is an easy-to-understand instrument that can be applied to patients with chronic diseases across different health care levels and has been widely used in Spain[14–15,17]. In addition to that, it incorporates a broader conception of integrated care, including social assistance and patient self-management, as well as the new technological interventions and interactions with the patients[12].

IEXPAC was developed in Spain and is structured with 11+1 items, where item 12 is a conditional question (global item) to evaluate recently hospitalized patients. The answers to this instrument are in the form of a *Likert* scale from "Never" to "Always", which yield a score from 0 (Worst experience) to 10 (Best experience) that evaluates the patient's experience and eases identifying aspects in health care that need to be improved[12]. Using this instrument can favor a more effective allocation of resources and investments in health towards more patient-centered care[12]. Currently, it is being adapted and validated for the reality of Portugal.

IEXPAC has been important for the practice and research in various Health areas, including Nursing. For its use in the Brazilian context, it was necessary to translate it, transculturally adapt it and evaluate its psychometric properties.

In view of this, the following was guiding question proposed: Is the adapted version of IEXPAC valid and reliable to assess CKD patients' experience? Thus, the objective of this study was to analyze the psychometric properties of the IEXPAC version adapted to Brazilian Portuguese.

METHOD

This is a methodological and cross-sectional study that analyzed validity and reliability of the adapted version of IEXPAC after its semantic and content adaptation for use in Brazil. Authorization from the IEXPAC authors was obtained to conduct its transcultural adaptation process.

The current study was carried out following these stages: translation of the instrument; synthesis of the translations; back-translation; consolidation of the translated version; semantic assessment of the items; content validation by a panel of judges; pre-test; application to the population; and metric data analysis[18].

The study population consisted of people with CKD. The adapted version of IEXPAC was applied to CKD patients undergoing hemodialysis in hospitals from the municipality of Campina Grande, Paraíba, Brazil. For this purpose, all four hospitals (three public and one private) that offer hemodialysis services to Unified Health System patients in the aforementioned municipality were chosen.

The sample was defined based on the guidelines proposed by Pasquali[18], which suggest that, for a sample to be considered appropriate, it is necessary to collect at least ten participants per item of the instrument undergoing validation. Consequently, as IEXPAC has 11+1 items, a sample of at least 120 individuals would be sufficient. Assuming losses in recruitment and other events, correction for a potential 10% loss was applied, which resulted in a sample comprised by 132 participants.

The inclusion criteria for this study were as follows: being aged at least 18 years old; being a chronic renal patient; and being on hemodialysis treatment for a minimum of six months. The six-month time frame was based on the IEXPAC recommendation, which defines this minimum period of time to assess the patients' experience.

Patients undergoing other types of treatments were excluded, as well as those with aphasia, significant hearing impairment and cognitive deficits that precluded understanding the interviews. The cognitive deficit assessment was performed with the Mini-Mental State Examination (MMSE), considering the cutoff values according to each interviewee's schooling level: 13 points was assigned to illiterate individuals, 18 for those with low (from 1 to 4 incomplete years) and average (from 4 to 8 incomplete years) schooling levels, and 26 points for those with high schooling (>8 years)[19].

The data were collected by the researcher in charge from July to October 2019 and via individual interviews. In the initial phase, the directors of each service were requested to provide an updated list containing the name, date of birth, gender and admission date of all CKD patients undergoing hemodialysis treatment. Using this information, it was possible to determine the number of participants per hospital, applying the proportional stratified sampling technique, with a simple random selection process.

Individual contacts with each participant were made at a private place in the hemodialysis sector, where the data collection instruments were applied. It was decided to conduct the interviews before the hemodialysis session, considering that the most frequent complications arise during and after such treatment.

Data about the sociodemographic characterization and the IEXPAC adapted version were collected. The instrument used for data collection was evaluated by experts in the theme, who concluded that the language and presentation of the items were appropriate for the study objective.

IEXPAC is structured into 11+1 items, with this latter one consisting in a conditional question (global item) to evaluate the patients that were hospitalized. The items refer to the previous six months, except for the question about hospitalization, which concerns the previous three years. All items are built on a *Likert*-type scale from zero to ten, which are represented as Never (0), Almost never (2.5), Sometimes (5.0), Almost always (7.5) and Always (10.0). The scale generates an overall score (the sum of all individual scores for the 11 items divided by 11) between 0 (Worst experience) and 10 (Best experience). In addition to that, it allows identifying the percentages corresponding to the categories of each item to determine which ones need to be improved[12–13,15].

In order to adapt IEXPAC, the stages recommended by the literature[18] were considered to achieve semantic, idiomatic, cultural and conceptual equivalence between the instrument versions (original and adapted). Consequently, the IEXPAC original version was initially translated to the Portuguese language by two bilingual translators and subsequently submitted to back-translation into the source language. The translated versions were consolidated afterwards. This version was evaluated by a committee of five judges to analyze semantic, idiomatic, cultural and conceptual equivalences, aiming to verify face and content validity. In addition, the semantic analysis was in charge of five individuals with low and average schooling levels.

The psychometric properties of the IEXPAC adapted version were analyzed with 132 CKD patients. Reliability of the instrument was assessed through internal consistency using *Cronbach*'s alpha, with a value of ≥0.70 considered acceptable[20]. Construct validity was evaluated through Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA). EFA is used to analyze the data structure, resulting in the identification of the instrument's factors/dimensions and of the

hypotheses to be tested. In turn, CFA is performed to confirm the hypotheses by presenting the factor structure of the instrument (factors, items and interrelations)[21].

Prior to conducting the EFA, overall sample adequacy was assessed using the *Kaiser-Meyer-Olkin* (KMO) measure and item adequacy was evaluated through the *Measure of Sampling Adequacy* (MSA). For KMO, the score should be ≥0.60 and, for MSA, it should be ≥0.50[22]. In addition, a hypothesis test was performed using Bartlett's sphericity test, which examines whether the covariance matrix is an identity matrix, analyzing whether there are no correlations[23].

Following the sample adequacy assessment, the EFA was performed using the *Weighted Least Square* (WLS) method, which is suitable for instruments with categorical or ordinal scales[24].

In order to obtain the CFA, the IBM® SPSS® AMOS 18.0 program was used. This analysis was carried out through Structural Equation Modeling (SEM), which verifies the factor structure through regression analyses between the items and the factors proposed. Based on SEM, theoretically relevant models can be specified and compared and first- and second-order factors can be identified. The model employed was the Weighted Least Squares Mean and Variance Adjusted (WLSMV) estimator, suitable for categorical or ordinal items. The following fit indices were considered: (χ^2), *Goodness-of-Fit Index* (GFI), *Adjusted Goodness-of-Fit Index* (AGFI), *Root-Mean-Square Error of Approximation* (RMSEA), *Comparative Fit Index* (CFI) and *Tucker-Lewis Index* (TLI)[25].

Composite Reliability (CR) and the Mean Extracted Variance (MEV) were also calculated in the CFA, with ideal scores for these indicators above 0.70 and 0.50, respectively[22].

The study was conducted according to the recommendations proposed in Resolution No. 466/2012 of the Brazilian National Health Council, and was approved by the Research Ethics Committee.

RESULTS

The following was observed among the 132 CKD patients who participated in the study: male predominance (54.5%), age ≥60 years old, married or with a partner (65.9%), from one to four years of study (48.5%), personal incomes of one minimum wage and family incomes between one and two minimum wages (81.0% and 61.4%, respectively), and retired individuals (54.6%).

In relation to internal consistency of the items from the IEXPAC adapted version, a *Cronbach*'s alpha value of 0.75 was obtained. Sample adequacy was observed by means of KMO = 0.735. In addition to that, Bartlett's test yielded a suitable result to perform the EFA [$\chi^2(36) = 260.241$; $p<0.001$]. In the MSA evaluation, it was observed that items 3 and 7 presented lower scores (0.34 and 0.29, respectively) than the recommended threshold (0.50); thus, they were excluded from the subsequent analyses. The other items were kept, as their values evidenced that they were adequate to perform the EFA.

Consequently, the EFA was carried out following the WLS method, which extracted one factor (Table 1).

For the CFA, the database with all the participants (n=132) was used. The SEM fit indicators to validate the scale confirmed IEXPAC validity, according to the criteria established. The results indicated the following values: $\chi^2/g = 1.129$; GFI = 0.96; RMSEA = 0.050; TLI = 0.97 and AGFI = 0.94.

The results obtained were confirmed in the prediction estimates, based on the regression analysis revealed for the model proposed. All the variables were significant and the criterion ratio was in line with what is established (t values > 2.58, p-value < 0.05). In addition to that, CR (0.952) and MEV (0.740) presented values above the ones recommended in the literature (Table 2).

Table 1 – Distribution of the items from the final adapted version of IEXPAC, according to one factor and commonality. Campina Grande – PB, Brazil, 2019. (n=132)

Items	Experience Overall Factor	h^2
4. Cuido-me melhor agora Sinto ter melhorado minha confiança e capacidade de cuidar de mim, administrar meus problemas de saúde e manter minha autonomia.	0.30	0.094
11. Incentivam-me a conversar com outros pacientes Os profissionais que me atendem me incentivam a participar de grupos de pacientes para compartilhar informações e experiências sobre como melhorar nosso cuidado e nossa saúde.	0.31	0.096
9. Preocupam-se com o meu bem-estar Os profissionais que me atendem se preocupam com minha qualidade de vida e o meu bem-estar.	0.49	0.240
1. Respeitam o meu estilo de vida Os profissionais que me atendem, me escutam, perguntam sobre minhas necessidades, costumes e preferências para realizar meu cuidado e tratamento.	0.54	0.295
10. Informam-me sobre recursos sociais e de saúde que podem me ajudar Os profissionais que me atendem me informam sobre os recursos sociais e de saúde que tenho disponíveis (no meu bairro, cidade ou povoado) para melhorar meus problemas de saúde e para me cuidar melhor.	0.55	0.297
8. Garantem que tomo a medicação corretamente Os profissionais que me atendem revisam comigo todos os medicamentos que eu tomo, a maneira como os tomo e os seus efeitos sobre mim.	0.58	0.336
5. Perguntam-me e ajudam-me a seguir meu plano de tratamento Reviso com os profissionais que me atendem o cumprimento dos cuidados e tratamento prescritos.	0.62	0.389
2. Estão coordenados para me oferecer um bom atendimento Os serviços da unidade de saúde e do hospital e os serviços sociais são organizados para melhorar meu bem-estar e qualidade de vida em meu ambiente.	0.62	0.383
6. Estabelecemos objetivos para levar uma vida saudável e controlar melhor a minha doença Tenho combinado com os profissionais que me atendem os objetivos específicos sobre alimentação, exercício físico e tomar medicação adequadamente para melhor controlar minha doença.	0.67	0.454
Eigenvalue	2.00	
Variance	37.00%	
***Cronbach's* Alpha**	0.75	

*h^2 – Commonality. The items present factor loadings ≥0.30, whose factors explain 37% of the construct variance.

Table 2 – Prediction estimates based on the regression analysis of the Experience construct. Campina Grande – PB, Brazil, 2019.

Reliability and Validity	Construct	Estimate	Standard Deviation	Criterion Ratio (t)[3]	p-value
CR* = 0.952	IEXPAC_1 Experience	0.571	0.091	6.259	0.001
	IEXPAC_2 Experience	0.439	0.107	4.112	0.001
	IEXPAC_4 Experience	0.344	0.099	2.644	0.001
	IEXPAC_5 Experience	0.769	0.079	9.717	0.001
	IEXPAC_6 Experience	0.773	0.078	9.854	0.001
	IEXPAC_8 Experience	0.468	0.106	4.415	0.001
MEV† = 0.740	IEXPAC_9 Experience	0.542	0.087	6.210	0.001
	IEXPAC_10 Experience	0.295	0.096	3.064	0.001
	IEXPAC_11 Experience	0.493	0.059	4.810	0.001

*CR = Composite Reliability; †MEV = Mean Extracted Variance

A path diagram was elaborated where the IEXPAC factor structure for Experience proved to be adequate to evaluate this construct (Figure 1).

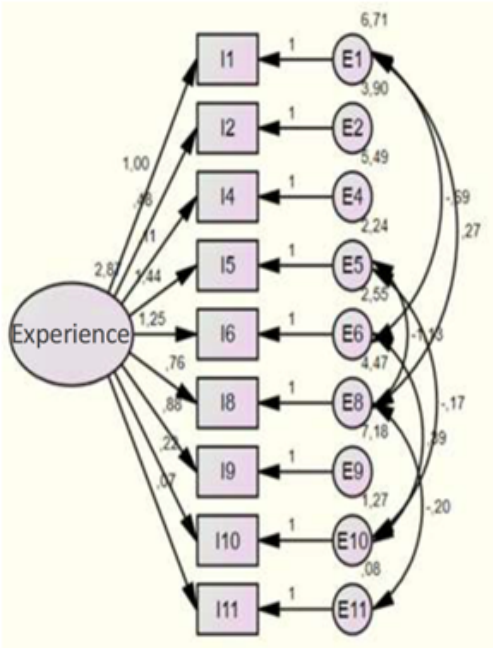

Figure 1 – Distribution corresponding to the IEXPAC Path Diagram. Campina Grande – PB, Brazil, 2019. (n=132)

DISCUSSION

The adapted version of IEXPAC underwent validation of its metric properties so that it was possible ensure that the instrument was capable of measuring what it is intended to assess. Construct validity was examined through EFA, which identifies the number of existing factors, and by means of CFA, which confirms the structural model of the instrument[21]. In this sense, it is emphasized that the validation process should be continuous and permanent in order to detect the need for changes in the instrument based on its application context[26].

The results of the sample adequacy tests (KMO and Bartlett's Sphericity) were significant, showing adequacy to perform the EFA[22,23]. In the sample-by-item adequacy assessment, item 3 (*"Ajudam-me a ficar informado pela internet"*) and item 7 (*"Uso internet e telefone celular para consultar meu histórico clínico"*) presented limited variability and weak correlation with the other items of the instrument; therefore, they had to be excluded. This result can stem from the context in which the study was conducted, as local initiatives that strengthen the process of incorporating and using health-related technologies are not a common practice. However, in the places that have these technologies, the suggestion is that these two items should be tested in the instrument.

It is understood that using health technologies is important to enhance the patients' experience, as employing these tools can complement health care, ease communication and provide educational support regarding the disease and the care measures required[27]. In addition to that, it can provide the opportunity for both patients and families to actively participate in the decision-making process regarding the care plan.

With the objective of exploring dimensionality of the scale, the EFA was performed to extract the maximum number of factors. In the original scale, three factors were extracted (productive interactions, new relational model, and patient self-management)[12]. In the adapted scale, considering the obtained alpha value and the number of items indicated per factor, it was decided to maintain the unidimensional structure, as the factor solution obtained was favorable both in terms of statistical analysis and meaning.

EFA is one of the most used procedures in the validation of psychological instruments. It aims at analyzing correlations among a large number of variables and at identifying those that are strongly interrelated (covariance), in order to determine the number of factors in the instrument[28].

The unidimensional structure explained 37% of the variance. A recent instrument validation study conducted in Brazil with patients with chronic diseases obtained variance values close to those in the current study[29]. However, there is still no consensus in the literature regarding which cutoff points for the explained variance level to be acceptable. Such being the case, when interpreting an EFA, its values should not be the sole consideration[30].

Commonality of the items indicates the extent to which the variance of each item is explained by the factors extracted in the factor analysis. In this way, its values vary between 0 and 1, with those closer to 1 indicating better variance explained by the factors[22]. In this study, the item that presented the highest communality value was *"Estabelecemos objetivos para levar uma vida saudável e controlar melhor minha doença"*: this implies that this item contributed the most to the statistical model adopted[31].

Regarding the factor loadings, all items presented values above 0.30, which is the recommended minimum[22]. To analyze reliability of an instrument, one of the most used methods to assess internal consistency (the interrelation degree between the variables) is to calculate *Cronbach*'s alpha coefficient, which evaluates the extent to which the items in a data matrix correlate with each other[18]. The alpha values can be influenced both by this correlation and by the number of items assessed, as factors with few items are more prone to presenting lower values[30].

The internal consistency of IEXPAC, assessed by means *Cronbach*'s alpha (0.75), was similar to the value found in the original scale (0.76)[12]. These results confirm that the adapted version of IEXPAC maintains internal consistency and upholds reliability of the original instrument.

The IEXPAC structural model was tested in the CFA with the objective of validating the structure obtained in the EFA, verifying fit of the structure corresponding to the observed variables in the instrument and confirming the theoretical model. The decision to apply the confirmatory model was based on its stricter nature, rendering it suitable for the validation of questionnaires[28].

In the CFA and considering the criteria established, unidimensionality of the instrument was confirmed, indicating good fits. MEV and CR also presented satisfactory results, which verified reliability

and validity of the construct evaluated. The path diagram indicated that the construct has a direct causal relationship with the observed variables and the latent variable, as evidenced by the good indices in a consistent model[32]. Therefore, it can be asserted that the factor structure of the adapted version of IEXPAC is appropriate and valid for measuring the construct in the sample under study.

The current study verified the validity of the IEXPAC Brazilian version. Validation of this instrument for Brazilian Portuguese intended to fill an existing gap in the field of care for patients with kidney disease. There is diverse evidence in the literature that evaluating patients' experience can provide significant data to ease improvements in care quality, clinical efficacy and patient safety for individuals with chronic diseases[12].

Given the complexity of caring for patients with CKD, more appropriate clinical management processes are necessary, characterized by actions encompassing prevention, control, treatment and monitoring that favor improvements in these patients' experience. A recent literature review revealed that the involvement of renal patients in their own care is still limited. In addition to that, it emphasized the need for health and social assistance providers to organize themselves to adequately meet the patients' needs at all times[33].

It becomes indispensable for health professionals assisting patients with chronic diseases to establish a relationship of trust, ease continuous interaction, understand the challenges faced and, based on that, develop strategies to enhance these patients' experience[34]. In this way, the experience of patients with CKD is relevant to identify their needs and to plan joint actions (patients, professionals and managers). In addition to that, it can favor the patients' active and collaborative participation in their own care and consolidate the provision of patient-centered care.

The limitations evidenced in this study were as follows: conducting the research exclusively with CKD patients, without evaluating its effectiveness with other chronic diseases such as malignant neoplasms, severe heart diseases and chronic respiratory conditions; generalization of the results is limited to patients living in a specific geographic region of the country, sharing certain behaviors that might influence the answers given to the instrument; finally, the inability to evaluate the psychometric properties of item 3 (*"Ajudam-me a ficar informado pela internet"*) and item 7 (*"Uso internet e telefone celular para consultar meu histórico clínico"*) due to the fact that the technologies pointed out in these items are not used in the services that took part in the research.

In this way, it is suggested to conduct longitudinal studies to identify the performance of IEXPAC at different moments. In addition to that, it is recommended to assess the psychometric properties of IEXPAC in other populations of chronic patients, in different health care contexts, with other methodological approaches, and using other types of measurements such as criterion validity and test-retest.

CONCLUSION

The adapted and validated version of IEXPAC for the Portuguese language presents semantic, idiomatic, cultural and conceptual equivalence as proposed in its original version, as well as satisfactory psychometric properties, considering its use for assessing the experience of patients with CKD undergoing hemodialysis. Unidimensionality of the instrument was recommended in the EFA and confirmed through CFA, with the indices indicating good fits.

Evaluating the patient's experience through IEXPAC may come to ease patient engagement in their own care, respect for their decisions by health professionals, incorporation of health technologies in the services, development of health education strategies and quality of life improvements, as well as strengthening the bond and productive interactions between patients, professionals and services.

In this context, IEXPAC can be used for research studies involving this population as an assessment and management instrument for the assistance provided to the patients. In addition, it can be incorporate into the integrated strategies for chronic care, in order to improve the quality of the services provided by health and social organizations, centers and professionals aiming to advance in patient-centered integrated care. Finally, it can be employed in teaching practices to support discussions on how to improve the experience of patients with chronic diseases. In addition to that, it may be used as a continuous assessment tool for the quality of the services provided.

This study also has implications in the scope of public policies, as it may raise reflections on the health care of people with CKD, about the roles of health professionals, services and administrators, and on the need for planning, targeting and implementing governmental actions aimed at improving health care services and quality of life for this population.

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NOTES

ORIGIN OF THE ARTICLE

Extracted from the thesis – Transcultural adaptation of *Instrumento de Evaluación de la Experiencia del Paciente Crónico* for Brazilian Portuguese in patients with chronic kidney diseases, presented at the Graduate Program in Nursing of *Universidade Federal da Paraíba*, in 2020

CONTRIBUTION OF AUTHORITY

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Discussion of the results: Bezerra TA, Pimenta CJL, Silva CRR
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APPROVAL OF ETHICS COMMITTEE IN RESEARCH

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CONFLICT OF INTEREST

There is no conflict of interest.

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SUPPLEMENTARY MATERIAL

The following online material is available for this article:
Versão Final Do *Instrumento De Evaluación De La Experiencia Del Paciente Crónico*