Translation, cultural adaptation and validation of Kidney Disease Loss Scale to the Brazilian context

Tradução, adaptação cultural e validação da *Kidney Disease Loss Scale* para o contexto brasileiro

Authors
Ana Carolina Ottaviani [1]
Fabiana de Souza Orlandi [1]

[1] Universidade Federal de São Carlos.

ABSTRACT

Introduction: Losses can be conceptualized as cognitive and affective responses to individual sorrows, characterized by brooding, yearning, disbelief and stunned feelings, being clinically significant in chronic diseases. **Objective:** The aim of the study was to translate, culturally adapt and validate the Kidney Disease Loss Scale into Portuguese. **Methods:** Validation study involving the steps recommended in the literature for healthcare instruments: initial translation, synthesis of translations, back translation, review by a committee of judges and pretest. **Results:** The scale was translated and adapted to the Portuguese language, being quick and easy to application. The reliability and reproducibility showed satisfactory values. Factor analysis indicated a factor that explains 59.7% of the losses construct. **Conclusion:** The Kidney Disease Loss Scale was translated, adapted and validated for the Brazilian context, allowing future studies of losses and providing tools for the professionals working in dialysis centers for assistance to people with chronic kidney disease.

Keywords: questionnaires; renal insufficiency, chronic; validation studies.

RESUMO

Introdução: As perdas podem ser conceituadas como respostas cognitivas e afetivas para tristezas individuais, caracterizadas pelo remoer, anseio, descrença e sentimentos atordoados, sendo clinicamente significativa em doenças crônicas. **Objetivo:** O objetivo do estudo foi traduzir, adaptar culturalmente e validar o *Kidney Disease Loss Scale* para a língua portuguesa. **Métodos:** Estudo de validação envolveu as etapas preconizadas na literatura internacional para instrumentos da área de saúde: tradução inicial, síntese das traduções, retrotradução, revisão por um comitê de juízes, pré-teste e avaliação das propriedades psicométricas. **Resultados:** A escala foi traduzida e adaptada para o idioma português, sendo de fácil e rápida aplicação. A confiabilidade e a reprodutibilidade apresentaram valores satisfatórios. A análise fatorial indicou um fator que explica 59,7% do constructo de perdas. **Conclusão:** A Escala de Perdas referente à Doença Renal foi traduzida, adaptada e validada para o contexto brasileiro, permitindo estudos futuros sobre perdas e instrumentalizando os profissionais atuantes em centros de diálise para assistência à pessoa com doença renal crônica.

Palavras-chave: estudos de validação; insuficiência renal crônica; questionários.

INTRODUCTION

Given its current high prevalence, chronic kidney disease (CKD) has received much attention from the scientific community, as per demonstrated in recent studies, becoming today a public health problem throughout the world.[1] According to data provided by the Brazilian Society of Nephrology in 2014 in Brazil, the estimated total number of patients with CKD was 112,004 - it should be noted that this figure represents an increase of 20,000 patients in the last 4 years. Among the types of dialysis, hemodialysis treatment corresponds to 91.0% of these patients. Dialysis treatment, though not replacing all kidney functions, maintains body homeostasis, relieving symptoms and preserving patients' lives.[2]

At the start of dialysis treatment, the individual has to undergo an adaptation

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Correspondence to:
Fabiana de Souza Orlandi.
Universidade Federal de São Carlos - Departamento de Gerontologia.
Rodovia Washington Luís, km 235, São Carlos, SP, Brazil.
CEP: 13565-905
E-mail: forlandi@ufscar.br

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process due to changes in one's routine life, which can lead to physical, psychological and social consequences.[3] ESRD patients experience multiple losses, resulting in stress and reflecting in the way patients cope with the disease and quality of life.[4]

The losses are conceptualization, impacting an affective response to individual sorrows, characterized by brooding, yearning, disbelief and stunned feelings, being clinically significant in chronic diseases.[5] CKD diagnosis is a factor of disruption, loss and intense psychological disorganization. In most instances, one finds a reaction of shock, followed by fear and anxiety. Each person experiences CKD in his/her own way, based on one's own history, culture and one's own way of coping with chronic health conditions and the need to perform the dialysis treatment.[4]

Faced with multiple losses, kidney patients often experience negative grief reactions, which can continue for years and affect their mental health. The loss should be considered a different construction of depression; losses are an event that, as a result, can cause symptoms of depression.[5] Depression-related losses were found in individuals with CKD and healthcare professionals as one of the important factors in psychosocial adaptation, adherence to treatment and quality life.[6] Therefore, studying loss is essential to understand how it is experienced by patients with CKD and how it affects other aspects of their lives.[7]

The Kidney Disease Loss Scale (KDLS) was developed in Australia to assess CKD-related losses. It is a scale made up of six items divided into two subscales, a cognitive loss one (four items), and another with the affective loss (two items), considering the individual nature of the losses.[5]

The KDLS asks respondents to name the five most important losses associated with their CKD, for classification purposes it involves affective and cognitive grief reactions. Later, participants rate their answers on four-point Likert-like scales, ranging from 0 (not applicable to all) to 3 (applicable to much or most of the time) for the named losses. The total score ranges from 0 to 18, and the higher the score, the greater the sense of loss from the assessed individual. Furthermore, KDLS enables a qualitative analysis of the losses reported by respondents.[7]

To date, there is no loss assessment tool for patients with chronic kidney disease developed or validated for use in Brazil. In this context, it is relevant to provide the aforementioned scale for use by the Brazilian chronic renal population. Given the above, the goal of this study was the KDLS translation, cultural adaptation and validation for use in Brazil.

Method

We conducted a validation study that included the following steps: initial translation, synthesis of translations, back translation, reviews by a committee of experts, pre-testing and evaluation of the psychometric properties of the instrument.[8]

The first step was the translation of the original instrument from English into Portuguese, made by two translators, independently, both fluent in English and with extensive experience in translating healthcare texts. For the second step, the researchers independently analyzed the translations, comparing them to the original version and defined in mutual agreement, the version to be used. In the third stage, the back translation, the consensus version was translated back to the original language, English, by two translators other than the ones from the first stage, both of whom did not receive information on the original version.

The next step was a peer review committee to assess semantic equivalence, idiomatic, cultural and conceptual versions. The expert committee was composed of seven bilingual scholar doctors, from different fields of healthcare, three nurses, one medical doctor and three psychologists. Besides these aspects, we involved people with expertise on nephrology or on validation of survey instruments.

The analysis of content validity by the members of the expert committee was held in two stages. First, the experts indicated the degree of content equivalence between the original version of the KDLS instrument and the consensus translated version. We used the Likert scale of 1 to 4 points for each item of the scale, where 1 = not equivalent; 2 = somewhat equivalent; 3 = equivalent; 4 = very equivalent.

For the analysis of the instrument's content validity we used the Content Validity Index (CVI), which indicates the proportion of experts in agreement on certain aspects of the instrument and its items. For CVI interpretation, we adopted the criteria by which, with six or more experts, it is not recommended to adopt a rate of less than 0.78. The index score was calculated by the sum of agreement concerning the items that received scores of "3" and "4" by the experts, divided by the total number of responses.[9]

In the next step, the final version was presented to 15 individuals with chronic kidney disease on hemodialysis. The participants were selected by simple random sampling and agreed to participate voluntarily. We intended to assess the degree of understanding of each question and that of the entire instrument. Upon finishing filling out the scale, we asked for suggestions from the participants, whether they have any difficulty in understanding the items that make up the instrument.

For the last step, the final version of the scale (Table 1), called Kidney Disease-Related Loss Scale (KDLS) was applied to 100 patients with CKD on hemodialysis. With this material it was possible to investigate the instrument's psychometric properties, reliability and validity.

The data was entered into a formatted Excel spreadsheet and transported for analysis in the Statistical Package for Social Sciences (SPSS for Windows), version 22.0 software. For a descriptive analysis, we calculated position measurements (mean, minimum and maximum) and dispersion (standard deviation). We used Cronbach's alpha (α) to check the internal consistency of the scale, the intra-class correlation index (ICI) to evaluate test-retest reproducibility and stability and the factor analysis to check the construct validity. The significance level for the statistical tests was 5% ($p \leq 0.05$).

It should be noted that before starting the process of translation, cultural adaptation and validation, we obtained the approval of the principal and corresponding authors of the KDLS. The study was approved by the Ethics Committee of the Federal University of São Carlos (Protocol No. 509.241). The project met the ethical standards in research involving human subjects.

Results

Translation and cultural adaptation

According to the theoretical framework adopted, the KDLS was submitted to translation into Brazilian Portuguese by two bilingual translators, who carried out the task independently. The two translations were compared by researchers to obtain a consensus translation. This comparison aimed to facilitate the conceptual and literary translation at the same time, and ensure the best meaning to the words in the

Table 1 KDLS Final version. São Carlos, Brazil, 2016

When you consider your life as it is now, with kidney disease and dialysis treatments, it is very clear that the present life is different from how your life used to be or could be. You can realize that you lost many things. We ask that you consider as LOSSES: things you did before renal disease/dialysis and now you cannot do or things you would be doing if you did not have kidney disease/dialysis. Please list below the five most important things you lost because of your kidney disease/dialysis.				
1:				
2:				
3:				
4:				
5:				
Regarding the five losses listed above, please read carefully each one of the following statements and circle the numbers 0, 1, 2 or 3 to indicate how much of the statement applies to you.				
The assessment scale is as follows:				
0 = Does not apply in any way				
1 = It applies to me in some degree or in part of the time				
2 = It applies to me in a considerable degree or in a large part of the time				
3= It applies to me very much or during most of the time				
1. I think so much about these losses that it is difficult to do the things I was used to doing	0	1	2	3
2. The memory of these losses upsets me	0	1	2	3
3. I am concerned with the thoughts about these losses	0	1	2	3
4. I wish I could recover what I lost	0	1	2	3
5. I cannot believe in what happened	0	1	2	3
6. I feel astounded or stunned by what happened	0	1	2	3

Brazilian Portuguese language and identify possible difficulties in interpretation and detect errors.

The KDLS translations held considerable similarity; however, the items that showed disagreement in translation, the translation used was the one the study investigators considered to be the one that best expressed the original sense of the term and better meaning to the Portuguese language. The scale was sent by email to the translators, who sent back the back-translated versions, which showed similarities with the original instrument in English. It was assumed that the consensus version and back-translations were suitable to be submitted to the expert committee.

The committee of experts judged the adequacy and clarity of the vocabulary and expressions used in the translated version of the scale, concerning semantic, idiomatic, cultural and conceptual equivalences. Of the 15 items, 10 were considered equivalent, with an agreement index of 1.00 and therefore maintained. It is noteworthy that the other five items showed CVI = 0.83, a rate higher than what requires retesting by the judges, but even with the support from the scientific literature, we reanalyzed again such items as per suggestions from the experts. It should be noted that we had a general average of 94% agreement in the analysis made by the experts.

The two back-translations were analyzed by the expert committee, which compared them to the original KDLS instrument. The experts independently choose the items between the two back-translations, i.e., they chose the semantic version that best compared to the original version. Both versions were sent to the corresponding author of the scale in order to ensure that all steps were strictly followed by them.

In the pre-test, the adapted version was well accepted by chronic renal failure patients, it was easy and quick to understand, taking on average 15 minutes for its application. They had no difficulty in understanding the meaning and clarity of the items on the scale. Thus, no question needed to be changed.

Evaluation of psychometric properties

After completion of the pre-test, we then started the last stage, the assessment of psychometric properties. The study included 100 patients with renal disease, with a predominance of males (66.0%) with a mean age of 53.25 (± 14.72) years. The average length of schooling was 8.41 (± 11.22) years, with a prevalence of subjects with 1 to 5 years of schooling (46.0%).

The mean total concerning the KDLS was 7.38 (± 5.19), with a range of 0 to 18. Regarding the subscales, the mean score was 4.40 (± 3.69) and 3.67 (± 2.50) for cognitive impairments and emotional losses, respectively. These results indicate a moderate sense of loss. Among qualitative KDLS results, we found that 62% reported losses concerning work/study; 44% had dietary restrictions; 40% had travel restrictions; 35% had impairments in physical activity; 20% had impairment on strenuous activity; 19% freedom restrictions; 17% had restrictions regarding family/personal relationships and 4% had low energy and sexual restrictions.

Regarding KDLS psychometric properties, Cronbach's alpha, used for internal consistency analysis had a value of 0.863. We found that the alpha showed no significant improvement when some item removed. Thus, the reliability was high, maintaining the original characteristics of the scale, after the stages of translation and cultural adaptation to Brazil (Table 2).

The test-retest carried out with 15 patients with CKD to investigate the KDLS stability between the first and the second application of the instrument, with 15 days difference between them, and found that there was no statistically significant difference between the uses ($p = 0.67$), indicating a high stability index (Table 3).

The Intra-class Correlation Index, used to check for KDLS reproducibility, showed a value of 0.98, being a high reproducibility indication, with p-value = 0.000 (Table 4).

To evaluate KDLS's factorial structure, we held an analysis of the principal components with varimax rotation. We should reiterate that a varimax rotation was used because KDLS is internationally recognized as a one-factor scale of losses. The results of the factorial analysis showed that the KMO index was 0.82 and the Bartlett sphericity test was significant ($p < 0.001$). This solution produced a factor with an eigenvalue of 3.58 and explained 59.7% of the total variance. The items with respective factor loads are presented on Table 5.

Discussion

The sample studied was described as to its sociodemographic characteristics, with a prevalence

Table 2 Analysis of internal consistency among the KDLS items. São Carlos, Brazil, 2016

Item	Mean score if the item is taken off	Score variance if the item is taken off	Correlation between the score and the item	Multiple correlation	Alpha if the item is taken off
KDLS1	6.70	18.59	0.717	0.561	0.829
KDLS2	5.90	18.07	0.698	0.576	0.833
KDLS3	6.37	18.49	0.707	0.536	0.830
KDLS4	5.10	20.25	0.535	0.315	0.861
KDLS5	6.66	20.06	0.662	0.534	0.840
KDLS6	6.73	19.95	0.631	0.537	0.845
Cronbach's Alpha					0.863

Table 3 Average scores obtained between KDLS test-retesting. São Carlos, Brazil, 2016

	Mean	Paired t-test
Scale of Losses score regarding Kidney Disease	7.38	0.670
Scale of losses concerning Kidney Disease - retest	7.35	

Table 4 Intra-class correlation Index (ICI) found in the test-retest, São Carlos, Brazil, 2016

ICI		95% Confidence Interval		*p*-value
		Lower threshold	Upper threshold	
KDLS and KDLS RT Score	0.996	0.986	0.994	0.001

of men and young adults, with full primary education. The issues outlined in this study corroborate the findings in national and international literature regarding characteristics of individuals with CKD.[10-15]

We should reiterate that CKD, in its terminal stage requires a process of losses and adjustments to the people who need this treatment. The loss is associated with coping, adherence to treatment and quality of life.[7] Therefore, studying the loss is essential to understand how it impacts the lives of patients with CKD and how it affects other aspects of one's life.

This study translated, adapted and validated the KDLS to the Brazilian context. Regarding KDLS, we obtained an average of 7.38 (± 5.19), and the range was from 0 to 18. As for the named losses, we highlight work/study (62%), food (44%) and travel (40%) restrictions, among others. In the study of the original version, the descriptive scale data was not reported; leisure and travel activities, decreased work/studies load and physical disabilities were named as important losses.[7]

Regarding the psychometric properties, we found that KDLS homogeneity (internal consistency) and reproducibility were investigated by analyzing the internal consistency and test-retest, respectively, with satisfactory results. The scale construction study analyzed the basic psychometric properties into three groups, one group of patients on long term dialysis (≥ 22 months), another in early dialysis (≤ 14 months) and the third on pre-dialysis (estimated glomerular filtration rate ≤ 20).[7] The internal consistency obtained in the study through the Cronbach's alpha was 0.88 in pre-dialysis; 0.91 in early dialysis and 0.88 in long-term dialysis. Reproducibility was measured by the test-retest and had a reliability value of 0.82.[5]

By analyzing the factorial structure, we concluded that the unifactorial solution was satisfactory for this set of items; it produced an eigenvalue factor of 3.58 and explained 59.7% of the total variance of losses in the context of CKD. In the investigation of the measurement properties of the original scale, the confirmatory factor analysis was performed on the estimation method of maximum likelihood using the Satorra-Bentler correction, indicating that the factor remained invariant between the groups, suggesting that the only factor of the scale with structure and load.[7]

Based on the proposed objectives and results obtained, we concluded that the KDLS was translated, adapted and validated to the Brazilian context, observing all the steps recommended in international scientific literature, being an instrument of easy

Table 5 Factorial analysis of the scale of losses items associated with kidney disease. São Carlos, Brazil, 2016

Component	Factorial load
1 – I think so much about these losses that it is difficult to do the daily things that I am used to doing	0.81
2 – The memories of these losses upset me	0.81
3 – I am concerned with the thoughts regarding these losses	0.80
4 – I feel a wish to recover what I lost	0.77
5 – I cannot believe what happened	0.75
6 – I feel shocked or stunned with what happened	0.66
Eigenvalue=3.58	
Explained variance =59.7%	
KMO=0.82	

understanding and application, which presented satisfactory psychometric properties.

The main limitation of this study refers to the convenience sample used for the analysis of the psychometric properties, in which the results cannot be generalized. The availability regarding the use of this loss assessment scale for the Brazilian population with CKD will empower healthcare professionals and researchers in qualifying and quantifying the losses suffered by people submitted to dialysis. This allows consideration of this important construct at the time of care and future research, thus helping in this quest to improve quality of life. We suggest that studies should be carried out in patients on pre-dialysis, peritoneal dialysis and transplant.

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