Original Article

Cross-cultural adaptation of the Bakas Caregiving Outcome Scale to Brazilian Portuguese

Adaptação transcultural da *Bakas Caregiving Outcome Scale* para o Português do Brasil

Adaptación transcultural de la *Bakas Caregiving Outcome Scale* al portugués de Brasil

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Abstract

Objective: To perform semantic and content validation of the Bakas Caregiving Outcome Scale for Brazilian Portuguese.

Methods: This is a methodological study, in which the cross-cultural adaptation was carried out according to international recommendations, and the content validation through a committee of judges. After these steps, the instrument was applied to a total of 151 informal caregivers of people with stroke sequelae, registered in Family Health Centers of Joao Pessoa, between September and December 2017. The internal consistency was verified by the Cronbach's alpha.

Results: By evaluating the committee of judges and carrying out the pre-test, content and semantics validation was achieved, with a Kappa index greater than 0.80. The general Cronbach's alpha was 0.89.

Conclusion: The instrument adapted and validated for Brazilian Portuguese proved to be reliable to be applied in the overload assessment of caregivers of patients with stroke sequelae.

Resumo

Objetivo: Realizar a validação semântica e de conteúdo da *Bakas Caregiving Outcome Scale* para o português do Brasil.

Métodos: Trata-se de um estudo metodológico, em que se realizou a adaptação transcultural segundo recomendações internacionais, a validação de conteúdo por meio de um comitê de juízes. Após essas etapas, o instrumento foi aplicado em 151 cuidadores informais de pessoas com sequela de acidente vascular encefálico, cadastrados em Unidades de Saúde da Família de João Pessoa, entre os meses de setembro e dezembro de 2017. Foi verificado a consistência interna pelo alfa de Cronbach.

Resultados: Mediante avaliação de comitê de juízes e realização do pré-teste, foi alcançada a validação de conteúdo e semântica, obtendo-se um índice de Kappa superior a 0,80. O alfa de Cronbach geral foi de 0,89.

Conclusão: O instrumento adaptado e validado para o português do Brasil mostrou-se confiável para ser aplicado na avaliação da sobrecarga de cuidadores de pacientes com sequela de acidente vascular encefálico.

Resumen

Objetivo: Realizar la validación semántica y de contenido de la *Bakas Caregiving Outcome Scale* al portugués de Brasil.

Métodos: Se trata de un estudio metodológico, en el que se realizó la adaptación transcultural según recomendaciones internacionales y la validación de contenido por medio de un comité de jueces. Luego de estas

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etapas, el instrumento fue aplicado con 151 cuidadores informales de personas con secuela de accidente vascular encefálico, registrados en Unidades de Salud de la Familia de la ciudad de João Pessoa, entre los meses de septiembre y diciembre de 2017. La consistencia interna fue verificada por el alfa de Cronbach.

Resultados: Mediante la evaluación del comité de jueces y la realización de la prueba piloto, se logró la validación de contenido y semántica con un índice de Kappa superior a 0,80. El alfa de Cronbach general fue de 0,89.

Conclusión: El instrumento adaptado y validado al portugués de Brasil demostró ser confiable para aplicarse en la evaluación de la sobrecarga de cuidadores de pacientes con secuela de accidente vascular encefálico.

Introduction

Cardiovascular diseases (CVD) represent one of the main causes of morbimortality worldwide.[1] Among CVD, the high prevalence of stroke stands out, which is characterized as a neurological syndrome resulting from a brain circulation disorder, which persists for more than 24 hours.[2] Stroke has a high incidence in all countries, with one case occurring every five seconds. In Brazil, this disease represents the main cause of mortality and disability, generating high costs for the government, especially due to the long hospital stay.[3]

After being discharged, the individuals commonly affected become dependent on the care of other people, which can be performed by a professional, named formal caregiver, or by an informal caregiver, without being paid.[4] Mostly, Informal caregivers are family members - spouses, adult children, other relatives or neighbors and friends - who may or may not live in the same house as the patient. Most of the time, only one person takes responsibility for caring, named main caregiver.[5]

Caregivers play an important role in promoting autonomy, independence and integration to the person affected by stroke, both in family setting and in social context. In addition, the interventions performed by them are essential to prevent hospital readmissions and institutionalization.[4] However, if they are not prepared to care, they may make it difficult to adhere to healthy behaviors and delay the patient's rehabilitation.[6,7]

Due to the complexity of activities performed by the caregivers, they have a high risk of developing overload, mainly due to the excess of functions, lack of support, not being prepared to care, the patient's level of dependence, the chronicity of the disabling situation, the complexity of care activities, the worsening of health status and the uncertainty of the future, which can result in social isolation, reduction or absence of leisure activities, impairment of professional activity, job loss and reduction of time to care for themselves.[8-13]

The overload, which derives from the term "burden", has been an object of considerable interest among researchers since the 1960s, changing over the years. Currently, it is defined as a phenomenon that varies from person to person, being multidetermined and referring to the perception of caregivers in relation to the impact of caring on their emotional, social, financial and physical functioning, in which it manifests when the demands of care are greater than the resources available.[14]

It is relevant to emphasize that the experience of overload for a long period of time contributes to the emergence of tension and stress, with changes in the physical, emotional and psychological state.[13-15] Thus, overload screening is essential for the planning of psychoeducational and psychotherapeutic interventions, seeking to strengthen the formal support network and improve the ability of caregivers to cope with the situation, in order to avoid or reduce overload and improve the quality of life of those involved.[16-18]

This assessment has been carried out mainly through scales. Two comprehensive reviews of caregivers' overload measures[19,20] indicated that the Caregiver Reaction Assessment scale[21] and the Bakas Caregiving Outcome Scale (BCOS) are the most complete. For this study, we decided to carry out the cross-cultural adaptation of BCOS, as it is sensitive to changes in the lives of caregivers of patients with stroke sequelae, detecting changes in self-esteem and in financial, emotional and social aspects that have occurred over time. In addition, it is one of the few developed with the guidance of a conceptual model for the development of items and validation tests.[22]

BCOS was created in the United States of America and then adapted and validated for Turkey

and Greece.[23,24] The original BCOS had evidence of reliability through internal consistency with a value of 0.90 and a 2-week test-retest, with an intraclass coefficient of 0.66. In addition, unidimensionality was supported by confirmatory factor analysis with indexes, indicating a good fit and the validity related to the criterion was supported by correlations with the health-related quality of life scale (SF-36) ($r=0.32$, $p<0.001$).[25] Longitudinal studies, carried out in other countries, have used BCOS to assess overload on caregivers' lives over the years and also on the effects of interventions to reduce it.[26,27]

Due to linguistic and cultural differences, it is necessary to translate it and make the cross-cultural adaptation to be used in Brazil by nurses and other professionals. Thus, this study aimed to perform the semantic and content validation of the Bakas Caregiving Outcome Scale for Brazilian Portuguese and to analyze the internal consistency of the instrument.

Methods

This is a methodological study for cross-cultural adaptation and validation of BCOS, built to assess caregivers' overload of patients with stroke sequelae, related to changes in life resulting from the provision of care.

Cross-cultural adaptation

To culturally adapt BCOS, Pasquali's recommendations were followed,[28] which seek to provide a semantic, idiomatic, cultural and conceptual equivalence between the original instrument and the adapted version.[29] Thus, the five following steps necessary for the cross-cultural adaptation of an instrument were carried out: translation, synthesis of translations, back-translation, evaluation by a committee of judges and pre-test, as shown in figure 1.

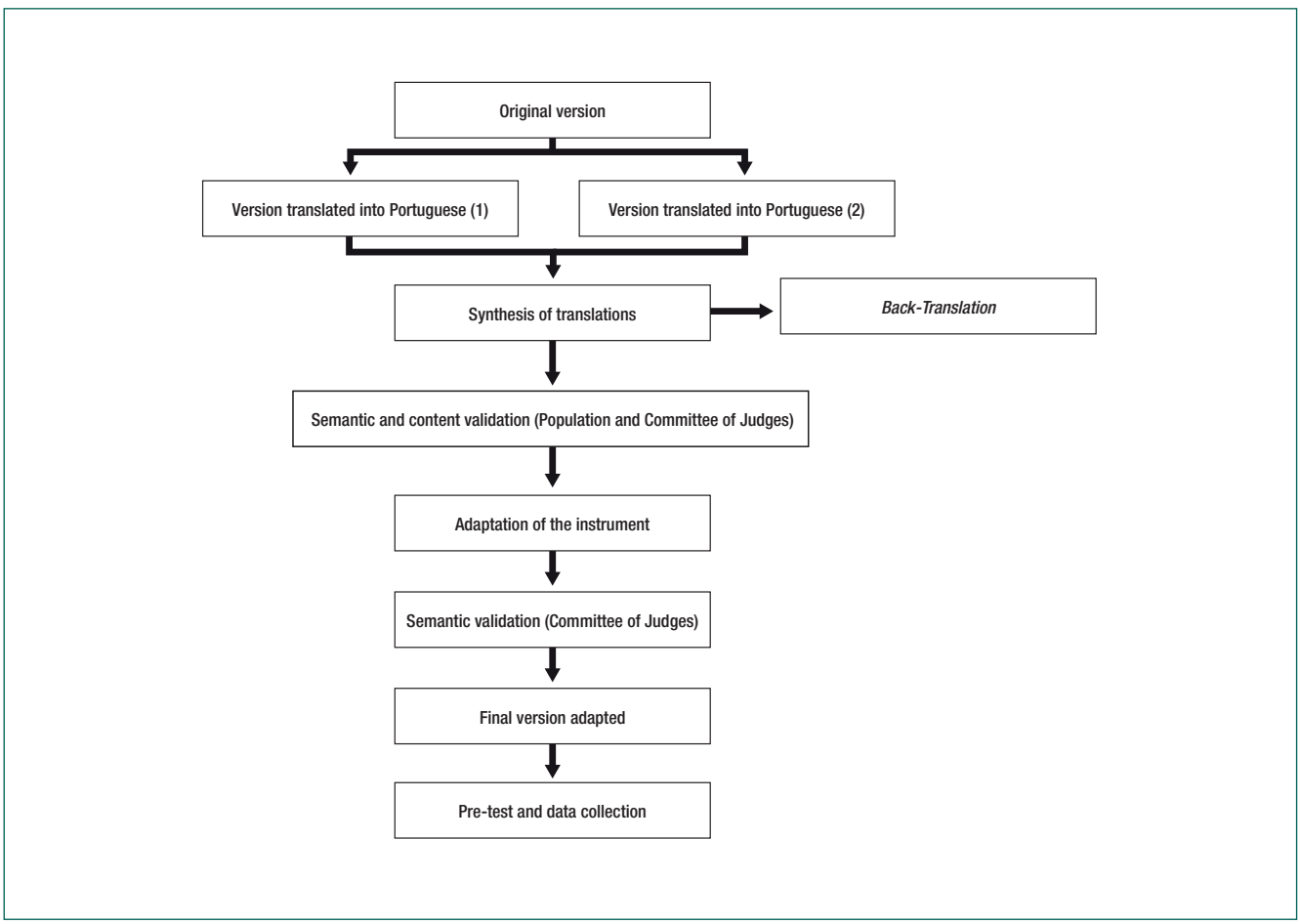

Figure 1. BCOS cross-cultural adaptation process

The original BCOS is a one-dimensional instrument that analyzes the changes that occurred throughout the life of the caregivers of these patients, based on the concepts of social function, subjective well-being and health. It was developed with a total of 48 items and, later, the short version was defined with 10 items.[30] In the most current version, five items were included, totaling 15 items, measured on a seven-point response scale ("Changed for the worse" = -3 to "Changed for the better" = +3), in which the lower the score, the greater the overload.[22] To obtain the score, it is necessary to recode all items (-3 = 1) (-2 = 2) (-1 = 3) (0 = 4) (1 = 5) (2 = 6) (3 = 7), with the average score obtained by simple calculation of the mean, with a minimum value of 10 and a maximum value of 70.

Initially, BCOS was translated from English to Brazilian Portuguese. Because of that, the original version was initially delivered to two Brazilian translators with experience in American culture, who have already lived in the United States for more than six years and who were not aware of the research objectives. In this study, the translated instruments were named "version translated into Portuguese (1)" and "version translated into Portuguese (2)".

Then, the synthesis of the translations was carried out by three PhD researchers, one of them is a psychologist with experience in cross-cultural adaptation of instruments and the other two are nurses with experience in the subject. The synthesis of the translations was sent to an American translator, who lives in Brazil for over ten years, and performed the back-translation of the instrument to the original language. This translator was also not aware of the objectives of the study.

The original, synthesis of the translations and the back-translation versions of the instrument were analyzed by two judges, in order to unify the preliminary version of the instrument. A researcher in the field with knowledge of the English language and the researcher participated in this process, in order to analyze the convergent and divergent points of the translations, minimizing the possible linguistic, psychological, cultural and compression bias found in the translation. After this process, the preliminary version of BCOS was structured, which was submitted to the semantic validation process.

The semantic analysis, which refers to the comprehension of the items on the scale, was carried out by three people, two of them had low level of education (incomplete primary school) and the other one had complete high school. At this time, content validation of the translated version was also carried out by a committee of five judges, who had academic training and a PhD in Nursing, having developed studies with informal caregivers.

The evaluated aspects were Language clarity: If the language used in the items is clear to the population; Theoretical relevance: Degree of association between the item and the theory, and between the item and the construct. To assess the degree of agreement among the judges, the Kappa index was used, which is an adjusted agreement indicator that ranges from "1 negative" to "1 positive" - the closer to 1 the better the degree of agreement among the observers; its distribution and the respective levels of interpretation are: < 0.00 = bad; 0.00 to 0.20 = weak; 0.21 to 0.40 = poor; 0.41 to 0.60 = regular; 0.61 to 0.80 = good; 0.81 to 0.99 = excellent; 1.00 = perfect.[29] As an acceptance criterion, an agreement greater than 0.80 among the judges was established.

Due to the difficulties in compressing the items of the instrument, verified in the previous step, it was decided to put a more detailed description of each item in parentheses, based on the suggestions made by the judges. A psychologist, a specialist in the subject and the researcher participated in this step. This version was again sent to the committee of judges for evaluation. After this, final adjustments were made in the scale, which was subsequently submitted to a pre-test with a total of 10 caregivers. As there was no problem with filling and understanding, the scale was considered appropriate for application with the population. The caregivers who participated in this step were included in the study sample.

Instrument application

The adapted BCOS was applied through individual interviews at the house of the caregivers of people with stroke sequelae, registered at the Family Health

Centers (FHC) in the city of Joao Pessoa - PB, between September and December 2017. The sample was defined based on Pasquali,[28] which suggests at least 10 subjects to be collected per item of the instrument that will be validated. Thus, as the BCOS is composed of 15 items, the sample consisted of a total of 151 subjects.

Inclusion criteria: being aged 18 or older and being a primary informal caregiver of patients with stroke sequelae, registered at the FHC in Joao Pessoa - PB. Formal and informal secondary or tertiary caregivers and caregivers of patients who had sequelae from other health disorders were excluded.

For participants selection, initially a random sequence of some FHUs from each of the five health districts was carried out. Then, we contacted nurses and community health workers (CHW) of each center, requesting, through the records, the address of people who suffered a stroke and had some sequel, identifying their caregivers. Data collection was carried out by the researcher and by students of the Undergraduate Nursing Course, who participated in the Scientific Initiation Program, with follow-up by a CHW, after previous training, which involved presentation, explanation and application of the scale among students for standardize the data collection process.

For socio-demographic characterization, the following information was collected: age, gender, marital status, educational background, professional situation, individual income, family income and income origin. The reliability analysis of the adapted version of BCOS was performed by measuring the internal consistency of the instrument items, calculated by the Cronbach's Alpha coefficient. The value attributed to this measure ranges from 0 to 1, in which the higher the value, the more the congruence among the items, indicating the homogeneity of scale.[31] If the exclusion of an item raised more than 0.1 of the domain total alpha, it would be excluded.[32]

BCOS adaptation and validation[33] was authorized, electronically, by Dr. Tamilyn Bakas, the leading author of the instrument, in accordance with Law N. 9610/98. The study was developed according to what is recommended by Resolution N. 466/2012 of the Brazilian National Health Council, with approval by the Research Ethics Committee.

Results

The semantic evaluation of the translated version of BCOS was carried out with the sample of caregivers, however, it was observed that the participants had difficulty understanding what most items expressed. The committee of judges evaluated the translated version according to the content (theoretical relevance and clarity of the items) and the semantics (understanding of the items), obtaining a Kappa below 0.80 in the clarity of almost all items for the population. As for relevance, there was an agreement on all items with an index equal to or greater than 0.80.

Due to the population's difficulty of understanding and the low level of agreement among the judges regarding the clarity of the items, it was decided to make an adaptation, based on the expressed suggestions, presenting a more detailed description of the items that obtained Kappa below 0.80 in the previous step, being named "adapted version". This version was again delivered to the committee of judges for evaluation, resulting in an increase in the agreement index in all modified items, with a Kappa greater than 0.80. The judges also made some suggestions to improve the quality regarding the clarity of the items, preparing the last version of the instrument, named "final adapted version" (Chart 1).

Among the 151 caregivers, there was a higher frequency of female (78.1%), aged between 56 and 65 years old (27.8%), married or in a stable relationship (65.6%), having five to eight years of education (27.2%), Catholic (60.9%), having an individual income of up to R$ 880.00 (44.4%) and family income of R$ 881.00 to R$ 1760.00 (41.7%), in which retirement was cited as the main source of income (32.5%), however, they did not consider this income to be sufficient to pay household expenses (58.3%).

For reliability analysis, Cronbach's alpha of the scale was calculated, with a total value of 0.898.

Chart 1. Semantic evaluation of the adapted version of the Bakas Caregiving Outcome Scale

Adapted version	Semantic evaluation	Final adapted version
1. My self-esteem (What I think about myself, my emotions and my behaviors in life)	No changes	1. My self-esteem (What I think about myself, my emotions and my behaviors in life)
2. My physical health (General condition of the body in relation to diseases and the physical capacity to carry out daily activities)	**From the original** 'Cotidiano'... **to the suggestion** "por dia-a-dia"	2. My physical health (General condition of the body in relation to diseases and the physical capacity to carry out daily activities)
3. My time for family activities	No changes	3. My time for family activities
4. My ability to deal with stress (Situations that I perceive as threatening)	No changes	4. My ability to deal with stress (Situations that I perceive as threatening)
5. My relationship with friends (Affection, friendship, love, loyalty and protection)	No changes	5. My relationship with friends (Affection, friendship, love, loyalty and protection)
6. My vision of the future (Ability to make plans in the near or distant future)	**From the original** '...elaborar planos num futuro próximo...' **to the suggestion** "...planejar o futuro próximo..."	6. My vision of the future (Ability to plan for the near future)
7. My energy level (Willingness to perform daily activities)	**From the original** '...as atividades do cotidiano...' **to the suggestion** "...as atividades do dia-a-dia"	7. My energy level (Willingness to perform daily activities)
8. My emotional well-being (Thoughts of joy and pleasure in daily experiences)	No changes	8. My emotional well-being (Thoughts of joy and pleasure in daily experiences)
9. Social roles (Mother or father, siblings, friends, son/daughter)	No changes	9. Social roles (Mother or father, siblings, friends, son/daughter)
10. My time for social activities with friends	No changes	10. My time for social activities with friends
11. My relationship with my family (Affection, friendship, love, loyalty and protection)	**From the original** '...com minha família...' **to the suggestion** "com parentes"	11. My relationship with relatives (Affection, friendship, love, loyalty and protection)
12. My financial stability (Organization with expenses, money control, savings)	No changes	12. My financial stability (Organization with expenses, money control, savings)
13. My relationship with stroke survivor (Affection, friendship, love, loyalty and protection)	No changes	13. My relationship with stroke survivor (Affection, friendship, love, loyalty and protection)
14. My physical functioning (My muscular strength, absence of body pain for daily activities)	**From the original** 'Cotidiano'... **to the suggestion** "por dia-a-dia"	14. My physical functioning (My muscular strength, absence of body pain for daily activities)
15. My health in general (Complete state of physical, mental, and social well-being and not only absence of disease)	No changes	15. My health in general (Complete state of physical, mental, and social well-being and not only absence of disease)

The reliability assessment, by excluding each of the 15 items, resulted in minimal changes in the total value, which would not justify the exclusion. Therefore, it was decided to maintain all items on the scale. In the overload assessment, a low general average (48.62) and a low average (below 4 = neutral value) were obtained for each item, except for the item "My relationship with stroke survivor", which obtained an average of (4.00). This result shows that caregivers perceived negative changes as a result of the provision of care.

Discussion

The elaboration and/or adaptation of a scale or psychological test is very complex, which requires the execution of many requirements related to its reliability and validity that are decisive for it to be effective. The cross-cultural adaptation of an instrument involves two fundamental phases: the assessment of conceptual and linguistic equivalences and the assessment of psychometric properties.[34] The BCOS - 15 adaptation and validation process went through the steps suggested by the literature,[28] which involved translation, synthesis of translations, back-translation and semantic and content validation with the target population and judges.

With regard to the translation of the scale into Portuguese, it is suggested that it be done by two translators, to minimize linguistic, cultural and understanding bias. Therefore, the translation cannot be done in a literally way, as in many circumstances it can result in incomprehensible sentences or not equivalent to the original meaning. Thus, choosing the translators is a relevant aspect of the translation process and it requires them to be proficient in both languages and familiar with the cultures associated with the language of the different groups.[35] The synthesis of the translations aimed to compare different versions and analyze the semantic, idiomatic, conceptual, linguistic and contextual discrepancies in order to have a single version.[36]

The back-translation of the scale resulted in few changes in the instrument statements, which did not affect the meaning and content of the scale items. This step is important to analyze what extent the translated version reflects the content of the instrument items, in accordance with the original version.[35] In the translation and back-translation

process, it was possible to compare the different versions and consolidate the translated instrument.

Therefore, the authors suggest that the translators are bilingual, have not participated in the first step and do not know the instrument. The objective is to correct possible translation errors that compromise the meanings of the items and to review misinterpretations that occurred during the translation and back-translation steps, which should be corrected. This technique is the most recommended, because it makes it difficult for a translator's bias to pass through the preliminary version. Through this method it is also possible to compare the data collections of the translated version and the original one.[28]

In the consolidation of the translations, the preliminary version that was delivered to both people with low education level and to expert judges, had misunderstandings in some items. So, it was considered pertinent to describe the meanings of the previously mentioned items based on the judges' suggestions, to avoid bias in the interpretation of both professionals and researchers who will apply the instrument, and informal caregivers. This aspect is extremely important, regarding a country as big as Brazil, with different behaviors, educational and socioeconomic levels and language. Thus, in order to standardize the application of the scale, it is important to have a clear explanation of each item, which is also carried out in other studies on cross-cultural adaptation of scales.[36-39]

The adaptation step has a significant relevance so that the instrument is appropriate for use in another context, considering the linguistic, cultural and idiomatic aspects of the country in which the instrument is being adapted.[35] In many circumstances, it is necessary to change or add words and/or statements, to guarantee the veracity and quality of the information collected.

The psychological assessment instruments depend, mainly, on the written language, which requires the adaptability of the items for the culture to which it is intended, in order to maintain the concept to be measured.[40] Thus, the cultural adequacy of a translated instrument allows its applicability and functionality to be equivalent to the original instrument in its respective country, by clarifying the obscure points in the translated text. This aspect improves interaction and communication when searching for information about what is aimed to be evaluated.

In addition to the adaptation steps of the instrument, statistical analyzes should be carried out to assess the extent to which the instrument can, in fact, be considered valid and reliable for the context to which it was adapted. Therefore, adapting and validating an instrument are distinct but complementary steps.[35] To test the psychometric properties of the "final adapted version", tests were used to validate the construct and criterion and assess the reliability of the scale.

With regard to the reliability of the adapted scale, the internal consistency performed by Cronbach's Alpha was 0.89, which reveals an internally consistent measure, since the reference value is 0.70 to 1.00. A similar value was found on the original 15-item scale[22] and in other validation studies in the English language, even for another population, such as cancer, whose alpha was 0.88.[41] Therefore, it is possible to ensure that BCOS adapted to the Brazilian context maintained the reliability of the original scale. Furthermore, in the exclusion of the items, there was no great difference in the alpha, thus, the 15 items were maintained on the adapted scale.

This study provides reflection and understanding about the importance and experience of the family, and especially the main caregiver, in the process of recovery and rehabilitation of patients with a disabling disease such as stroke, inserting them as people who also need health care. Informal caregivers have a hard but important job in rehabilitation, social integration and motivation for the person in their care. However, it becomes difficult to provide qualified care when experiencing negative changes in life. Thus, it is relevant to assess the perception of the impact that the provision of care has on the caregiver's life.

The limitations evidenced in this study were related to the restriction of the research to be carried out only with caregivers of individuals with stroke, making it impossible to evaluate its effectiveness in

other caregivers, such as those who care for children with a disease, people with mental disorders, cancer, disabilities, among others. The generalization of the results is also limited to caregivers who live in only one geographical region of Brazil, who have specific customs and culture, which can influence the responses of the instrument. It is suggested that further psychometric studies be carried out to assess the instrument construct and criterion validity.

Conclusion

In the process of cross-cultural adaptation of BCOS-15 to Brazilian Portuguese, conceptual, semantic and measurement equivalences were maintained as proposed in the original version. The scale in the Brazilian context is promising for assessing the overload of caregivers of people with sequelae of stroke, as it is sensitive enough to detect changes in their lives. As it is a brief and easy-to-administer instrument, it can be a valuable tool for nurses to use to assess caregivers' overload at all levels of health care. In addition, it can also be used to identify the dimensions that had the greatest damage in the caregivers' life, due to the provision of care, helping to define priority areas for interventions and to record their progress over time.

Collaboration

Costa TF, Pimenta CJL, Silva CRR, Bezerra TA, Viana LRC, Ferreira GRS e Costa KNFM declare that they contributed to the design of the study, analysis and interpretation of the data, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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