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Brazilian transcultural adaptation of the "Family caregiver-specific quality of life scale": a methodological study

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ABSTRACT

Aim: To perform a transcultural adaptation of the Family Caregiver-Specific Quality of Life Scale to be used in Brazil. **Method:** A simple, easily applicable questionnaire was applied, composed of 16 questions, subdivided into the physical, psychological, social and spiritual domains, which was originally tested on a population composed of caregivers for heart failure patients. In this methodological study, the process of adaptation involved the translation, synthesis of translations, back translation and a committee of evaluators. **Results:** After the translation process, the committee of evaluators suggested some changes to the questionnaire that were authorized by its original author. **Discussion:** The questionnaire was considered pertinent to Brazilian culture, and to adequately represent the target-population, as well as presenting a good semantic equivalence between the final version in Portuguese and the original version. **Conclusion:** The instrument has proven to be sufficiently adequate to be used in the general population, and it has also been psychometrically validated.

Descriptors: Caregivers; Quality of life; Questionnaires; Translating

INTRODUCTION

Heart failure (HF) is a common outcome for a large number of diseases that affect the heart; it is also one of the most important clinical challenges today, in the area of health. It is an epidemic problem, which is still increasing, and it is the most frequent cause of hospitalization due to cardiovascular diseases in Brazil[1].

There is an estimate that in 2025 five million people will have HF in Brazil. This represents a serious public health issue around the world, which is due to the great technological and therapeutic developments in the area of health[2,3].

A caregiver is usually needed to support or even to assist in the daily routine of HF sufferers as it is a chronic and debilitating disease, which places many limitations on the patient[4].

The caregiver has a close bond with the patient, and they care for them in the best possible way, for no financial benefit; they eventually somatize the caring process, positively or not. The majority of the studies performed regarding the caretaking process focus on the overcharge on the caregiver and the physical, psychological and financial demands that they face [5,6]. However, some caregivers mentioned positive aspects, such as personal fulfillment, pride in the ability to take decisions, and improvement in self-esteem[7].

The caregiver has an important role in the treatment, participating actively in decisions, and has strong influence on the adherence of the procedures. However, they also have to adapt to deal with the responsibilities of caring, meaning that that they do not prioritize their own needs, which impacts upon their own quality of life [4,8-10]. Caregivers are usually women, either wives or daughters, who are around 49 years old and perform such a role for about five years[5,9].

In Brazil, the lack of studies about caregivers is evident, especially those aimed at evaluating the quality of life of caregivers for HF patients. Up to now, there have been no specific, validated instruments to evaluate the quality of life of these caregivers in the country.

The construction of new instruments demands efforts and the considerable use of valuable financial resources. On the other hand, the adaptation of existing instruments from other languages, besides having great scientific relevance, permits the comparison of data among samples from multi-centered studies[11,12].

Historically, the adaptation of instruments originating from other cultures was simplified by a simple and literal translation of the words, which compromised the quality of the displayed information[13]. Today, researchers demonstrate that both transcultural adaptation and literal translations are needed to emphasize the semantic equivalence and to ensure that keywords make sense to the target population. Hence, there is a necessary fine-tuning with the cultural context of the target population, especially in a heterogenic country such as Brazil, where the differences in communication, creed and culture are evident[13].

A study took place, which aimed to build a valid instrument that could assess the quality of life of caregivers of HF patients; focusing on determining the psychometric proprieties of an instrument composed initially of 46 items, it measured the perception of well being of relatives/caregivers regarding their responsibilities. After the evaluation of the psychometric proprieties, the deletion of some items and the inclusion of others, a specific questionnaire was built to evaluate the quality of life of caregivers of patients with HF. This was called *Family Caregiver-Specific Quality of Life Scale,* which was previously known as 16-item *Heart Failure Family Caregiver-Specific Quality of Life Scale*. This questionnaire was validated in 2007 in the United States of America, on a population of caregivers of HF patients, and up to this moment, there wasn't any trans-

Vieira GCA, Cavalcanti ACD, Silva AS, Guimarães TCF, Rosa MLG, Silva VA. Brazilian transcultural adaptation of the "Family caregiver-specific quality of life scale": a methodological study. Online braz j nurs [internet]. 2014 Mar [cited year mouth Day]; 13 (1): 53-61. Available from: http://www.objnursing.uff.br/index.php/nursing/article/view/4577

cultural adaptation of this instrument in other countries[14].

The *Family Caregiver-Specific Quality of Life Scale* is relatively short, easily applicable, and composed of 16 questions, which are subdivided into four domains: physical, psychological, social and spiritual. The score varies from 16 to 80 points, with 80 signifying a better quality of life[14].

Based on these considerations, we aim to create a transcultural adaptation of the *Family Caregiver-Specific Quality of Life Scale* that can be used in Brazil.

METHOD

This methodological study was approved by the Committee of Ethics in Research in Human Beings, of Fluminense Federal University, under protocol 11017412.9.0000.5243. The process of transcultural adaptations followed the guidelines described in literature[13], which is based on the following steps: initial translation; synthesis of translations; back translation and committee of evaluators.

All changes applied during the process of transcultural adaptation of the instrument into Portuguese were performed after authorization of the original instrument. The steps are described as follows (Image 1):

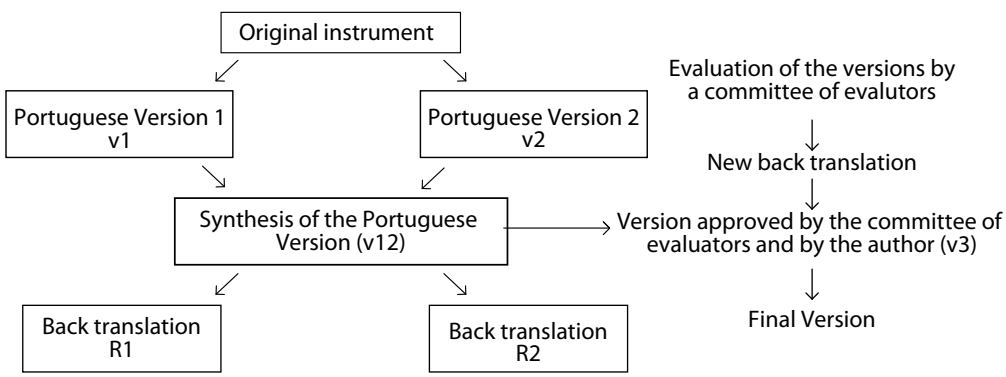
Translation

In this first step, two notarized Brazilian translators, both fluent in the first language, made two separate translations from the original instrument in English to Portuguese. They worked independently and were not familiarized with the original version of the questionnaire, being informed only of the objectives of this research. They were asked not to translate words literally, but to also focus on semantic equivalence. From this process, two versions were created: V1 and V2, which were studied and analyzed by two researchers. One of which is a doctoral student and the other a Masters student, both are nurses with over five years experience in the field of HF. Together, they synthesized the versions produced, generating a third document, the version V12.

Back translation

This stage was performed by two North-American translators, fluent in Portuguese,

Image 1- Flowchart of the steps taken to create a transcultural adaptation of the *Family Caregiver-Specific Quality of Life Scale*. Niterói, Brazil, 2013



Source: Designed by the authors, 2013

who worked on the synthesis of the translations (V12). Both performed their roles independently and were unaware of the original version, thus producing two back translations (R1 and R2).

Committee of evaluators

A multidisciplinary team formed the committee; comprising of a PhD nurse, a nurse who works with HF patients, two physicians, one epidemiologist, an English teacher and the researcher. A meeting was scheduled on February 21st 2013, when the members were present and had access to all the versions produced previously (V1, V2, V12, R1 and R2), besides the original document.

The researcher gave a presentation, explaining the aim of this study, the profile of the target population, the methodology, and which aspects needed to be observed in order to generate a final questionnaire that was easy enough to be fully understood, and which is semantically equivalent to the original one.

The committee worked directed for the questionnaire in general, for each question, for the scores for each of the four areas and issues that comprise them.

In the end, there was a consensus that generated an adapted version (V3), and it was unanimously requested that this version also had a back translation, in order to verify whether the proposed questions had the same meaning in the original language. Therefore, the adapted version (V3) was back translated by two independent North-American translators, both fluent in Portuguese, generating two new versions V4 and V5.

After the analysis of the new back translated versions, the members of the committee concluded that the proposed adapted version (V3) was coherent with the original document in English, and endorsed the conclusion of this step of the process.

The version approved by the committee of evaluators was sent to the author of the study, who added two considerations: (i) in regards to question number five (Due to the role as a caregiver, my health is shaken), declaring that it would be balanced to the physical domain, which is the domain where it belongs; (ii) they also discussed whether questions 2 and 6 were clearly different, which corresponded respectively to the following sentences: As a caregiver, I feel overwhelmed; and Due to the role of caregiver, I am emotionally exhausted. Her questions were answered promptly, and as a consequence, it was finally approved as the Brazilian version.

RESULTS

The stage of translation and back translation can be observed on Chart 1. After committee's analysis of the original version, translated and back translated, there were no modifications regarding either its structure or the score of the instrument. The suggested changes aimed to provide better understanding of the instrument and all were added to the document, as they were approved by 100% of the evaluators.

After the committee's evaluations, the following changes were performed:

Each question will be accompanied by its corresponding title, which means that questions 1, 2 and 3 will start with the expression "As a caregiver". This is different from the original version, as this title was placed first, followed by the questions.

- Question 1 – The sentence "seems I get sick more frequently" was replaced by "As a caregiver I think I get sick more frequently". The word "think" was considered to be more adequate to Brazilian culture and for the caregivers.

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Chart 1 - Stages of translation and back translation of the *Family Caregiver-Specific Quality of Life Scale*. Translation performed in Dec/12; Back translation performed in Jan/13. Niterói, Brazil, 2013.

	Original instrument	Translation	Back-translation
	As a caregiver	**T1- Como cuidador (a),**	**T1- As a caregiver**
		T2- Como cuidadora	**T2-As a caregiver**
1	I seem to get sick more often.	T1- Parece que fico doente com mais frequência	T1- It seems like I get sick more often
		T2- Tenho a impressão de ficar doente com mais frequência	T2- Seem to get sick on a more frequent basis
2	I am overwhelmed.	T1- Fico sobrecarregado (a)	T1- Feel Overloaded (a)
		T2- Fico sobrecarregada	T2- Feel Overworked
3	I feel selfish when considering my own needs	T1- Sinto-me egoísta quando penso nas minhas próprias necessidades	T1- I feel selfish and consider my own needs
		T2- Me sinto egoísta ao considerar minhas próprias necessidades	T2- I feel selfish and only consider my own needs
	Because of caregiving	T1- Devido à atividade de cuidador (a)	T1- Due to the activity as a caregiver
		T2- Por causa da prestação de cuidados	T2- Because of the activity as a caregiver
4	I am tired.	T1- Sinto raiva	T1- I feel tired
		T2- Estou cansada	T2- I feel tired
5	My physical health has suffered.	T1- Minha condição física sofre	T1- My physical condition suffers
		T2- Minha condição física foi prejudicada	T2- My physical condition suffers
6	I am strained emotionally	T1- Fico emocionalmente esgotado (a)	T1- I feel emotionally broken down
		T2- Estou emocionalmente esgotada	T2- I feel emotionally overwhelmed
7	I am socially isolated.	T1- Fico socialmente isolado (a)	T1- I am socially isolated
		T2- Estou socialmente isolada	T2- I fell all alone
	Even though I am a caregiver,	T1- Embora eu seja cuidador (a)	T1- Although I am a caregiver
		T2- Embora eu seja cuidadora	T2- Even though I am a caregiver
8	I am still able to exercise like I want	T1- Consigo me exercitar como desejo	T1- I can still work the way that I want
		T2- Ainda consigo me exercitar como eu quero	T2- I can still workout the way I want
9	I am able to get to my own checkups with doctors, dentists,and other health care providers.	T1- Consigo marcar consultas de rotina com médicos, dentistas e outros profissionais de saúde	T1- I can schedule routine appointments with doctors, dentists and other health professionals
		T2- Consigo fazer meu próprios exames com médicos, dentistas e outros prestadores de assistência médica	T2- I can schedule exams with doctors, dentists and other health professionals
10	I am able to participate in enjoyable activities.	T1- Consigo participar de atividades agradáveis	T1- I can participate in enjoyable activities
		T2- Consigo participar de atividades agradáveis	T2- I can participate in fun activities
11	I am able to maintain personal relationships with others.	T1- Consigo me relacionar com outras pessoas	T1- I can have good relationshipd with people
		T2- Consigo maanter relações pessoais com outros	T2- I am able to relate with other people

12	I am able to practice religious activities if I want to.	T1- Consigo manter atividades religiosas, se quiser	T1- I Keep religious activities when I want to
		T2- Consigo praticar atividades religiosas, caso queira	T2- I can maintain religious activities when I want to
	Caregiving,	T1- Ser cuidador (a),	T1- Caring,
		T2- Cuidar,	T2- Taking care,
13	Adds to my purpose or mission in life	T1- Contribui para meu objetivo ou missão na vida	T1- I add to my purpose and mission in life
		T2- Acrescenta ao meu propósito ou missão na vida	T2- I always add to my purpose and mission in life
14	Adds to my feelings of inner strength.	T1- Contribui para meu fortalecimento interior	T1- I contribute to strengthen my inner self
		T2- Acrescenta ao meu sentimento de força interior	T2- I strengthen my inner self
15	Gives me a sense of inner peace	T1- Confere uma sensação de paz	T1- It gives me a sense of inner peace
		T2- Me dá uma sensação de paz interior	T2- I have a sensation of inner peace
16	Gives meaning to my life.	T1- Dá sentido à minha vida	T1- It make sense to my life
		T2- Dá sentido à minha vida	T2- It makes sense in my life

Source: Nauser, 2011[14]

- Question 2 – "I am overcharged" was substituted by "As a caregiver, I feel overwhelmed", as the title followed the questions, and the word "feel" suggests an idea of a constant situation, the opposite of a momentary stage, represented by the verb "to be".
- Question 3 – The expression "taking into account" replaced the word "consider", as the committee thought it is easier to understand.
- Questions 4, 14, 15 and 16 – the titles were added to the question, without any further change.
- Question 5 – "My physical condition suffers from" was replaced by "Due to my role as a caretaker, I feel tired", as the first format could generate some difficulty in understanding, as the terminology is not common in Brazil.
- Questions 6 and 7 – The evaluators decided to use the verb "to be", in place of "to get", to give an idea of a current situation that is not simply temporary.
- Question 8 – The expression "the way I want" was added at the end of the sentence to clarity that it refers to any exercise according to the choice of the subject.
- Question 9 – The phrase "my own consultations" was inserted to emphasize that at this moment we are concerned with the caregiver's health, avoiding any sort of misconception.
- Question 10 – "The way I want" was inserted in the place of "pleasant" to make it clear for the caregiver that it refers to the activities this person likes to perform and that are not interesting to all.
- Question 11 – The committee pointed out it was relevant to make clear the types of relationships mentioned by the question, and therefore it was changed to "Besides I am the caregiver, I can keep my friends".
- Question 12 – The verb tense was changed to adapt to reality.
- Question 13 – The section "Taking care contributes for my life goal, my mission in life", as the words "purpose" and "add" could generate doubts.

The synthesis version and final version, designed after the appraisal of evaluators, are presented in Table 2, as follows:

After the above-mentioned modifications, the final product was sent to the author of the original document, who approved the changes.

DISCUSSION

This study was the first in Brazil to present a transcultural adaptation of the *Family Caregiver--Specific Quality of Life Scale*, an instrument that evaluates the quality of life of caregivers of patients diagnosed with HF. According to information shared by the author of the original questionnaire, there are ongoing studies to validate this instrument in the United Kingdom, Italy, Denmark and China, but until now no research has been published.

Through the transcultural adaptation of the instrument for its application on the Brazilian population, there was a careful and solid process of translation that enables future studies, using the adapted document with the same accuracy as it was used to build a new instrument[11,15].

With the consent of the committee of evaluators, simple, clear and easy to understand terminology was inserted for the caregivers of HF patients, as some studies affirm that, in Brazil, these people have between 5 and 6 years of

Table 2 - Synthesis of translations and final version of the *Family Caregiver-Specific Quality of Life Scale* after the final decision of the committee of evaluators. Niterói, Brazil, 2013

Colunas1	Synthesis of the translation	Version after the committee of evaluators
	As a caregiver	
1	I seem to get sick more often	As a caregiver I seem to get sick more often
2	I am overwhelmed	As a caregiver I am overwhelmed
3	I feel selfish when considering my own needs	As a caregiver I feel selfish when considering my own needs
	Because of caregiving	
4	I am tired	Because of caregiving, I am tired
5	My physical health has suffered	Because of caregiving, my physical health has suffered
6	I am strained emotionally	Because of caregiving, I am strained emotionally
7	I am socially isolated	Because of caregiving, I am socially isolated
	Even though I am a caregiver,	
8	I am still able to exercise like I want	Even though I am a caregiver, I am still able to exercise like I want
9	I am able to get my own checkups with doctors, dentists and other health professionals	Even though I am a caregiver, I am able to get my own checkups with doctors, dentists and other health professionals
10	I am able to participate in enjoyable activities	Even though I am a caregiver, I am able to participate in enjoyable activities
11	I am able to maintain personal relationships with others	Even though I am a caregiver, I am able to maintain personal relationships with others
12	I am able to practice religious activities if I want to	Even though I am a caregiver, I am able to practice religious activities if I want to
	Caregiving,	
13	Adds to my purpose or mission in life	Caregiving adds to my purpose or mission in life
14	Adds to my feelings of inner strenght	Caregiving adds to my feelings of inner strenght
15	Gives me a sense of inner peace	Caregiving gives me a sense of inner peace
16	Gives meaning to my life	Caregiving gives meaning to my life

Source: Designed by the authors, 2013

education, on average[16,17]. Regional slang was avoided as Brazil is a country with many different cultures living together thus prioritizing the expressions that are recognized nationwide[18].

The new back translation required by the committee of evaluators, in conjunction with the exchange of information with the author of the original instrument, guaranteed the semantic equivalence between the original document in English and the instrument generated in Portuguese.

Studies have been developed with many methodologies, in order to perform the transcultural adaptation of instruments of evaluation. These demonstrate that there are differences of life habits in different cultures that can make one item of the questionnaire be more or less difficult to understand, thus it is necessary to have a later study to evaluate the equivalence of measurement[12,19,20]. Hence, the adapted instrument will equally measure the concept in different cultures, and the results can be compared.

The present study had an important initial stage that applied and evaluated the instrument of quality of life of caregivers of HF patients in Brazilian epidemiologic samples, and possible comparisons with other samples.

A limitation found in this study was the lack of references about the quality of life of caregivers of HF patients that used this instrument, as it had not yet been adapted and translated to other languages.

CONCLUSION

The generated instrument showed that it could adequately measure the quality of life of caregivers of patients diagnosed with HF. However, it is important to highlight that transcultural adaptation is the first step of all processes of validation. The Brazilian authors began this process and it is important that readers are cautious before the publication of these results.

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