Cross-cultural adaptation of the Caregiver Reaction Assessment for use in Brazil with informal caregivers of the elderly

Adaptação transcultural do Caregiver Reaction Assessment para uso no Brasil com cuidadores informais de idosos

Adaptación transcultural del Caregiver Reaction Assessment para empleo en Brasil con cuidadores informales de ancianos

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ABSTRACT

Objective: This study aimed to carry out the cross-cultural adaptation of the Caregiver Reaction Assessment (CRA) for use in Brazil with informal caregivers of dependent elderly. Method: A methodological study, of five steps: initial translation, synthesis of translations, retro-translation, evaluation by a judge committee and a pre-test, with 30 informal caregivers of older persons in Fortaleza, Brazil. Content validity was assessed by five experts in gerontology and geriatrics. The cross-cultural adaptation was rigorously conducted, allowing for inferring credibility. Results: The Brazilian version of the CRA had a simple and fast application (ten minutes), easily understood by the target audience. It is semantically, idiomatically, experimentally and conceptually equivalent to the original version, with valid content to assess the burden of informal caregivers for the elderly (Content Validity Index = 0.883). Conclusion: It is necessary that other psychometric properties of validity and reliability are tested before using in care practice and research.

DESCRIPTIONS

Aged; Caregivers; Cross-Cultural Comparison; Validation Studies; Geriatric Nursing.
INTRODUCTION

The task of providing care to a dependent elderly imposes numerous requirements on the informal caregiver. This can lead to burden, a complex and multidimensional phenomenon that usually occurs when the caregiving experience and the growing demands of the elderly care require the caregiver to go beyond their ability\(^1\),\(^2\), causing them emotional, social and physical damage\(^3\),\(^4\).

Studies with elderly caregivers indicate psychological distress, anxiety\(^5\), depression\(^6\), stress\(^7\) as well as physical problems and poorer quality of life related to health when compared to non-caregivers\(^8\),\(^9\).

It is known that the support to family caregivers of elderly consists of new challenges for the Brazilian health system, given the rise in the number of elderly in the population\(^10\). The evaluation and monitoring of caregiver burden contributes to action planning, adapted healthcare services and training of staff to support families with their specific needs\(^11\), benefiting caregivers and elderly care\(^12\).

In this sense, the use of appropriate measurement tools is relevant in order to propose effective interventions. In international literature, there is the Caregiver Reaction Assessment (CRA), developed in the United States by researchers at Michigan State University, whose purpose was to obtain a multidimensional tool suitable for burden assessment of family caregivers of people suffering from chronic physical and mental diseases\(^13\),\(^14\), which makes it particularly suitable for use among family caregivers of dependent elderly.

The instrument consists of 24 items, grouped into five subscales that assess both the negative aspects as well as the positive aspects of supplying informal care. The CRA has been widely used in different continents, which in addition to being a wealth of information on the burden of informal caregivers throughout the world, can also ensure comparisons in different scenarios of research.

The instrument has been translated and validated in Germany\(^15\), Netherlands\(^16\), Sweden\(^17\), Norway\(^18\), Portugal\(^19\), Korea\(^20\), Japan\(^21\), China\(^22\) and Singapore\(^23\), revealing satisfactory parameters of validity and reliability in different cultures. This provides adequate evidence of its multicultural equivalence and encourages the implementation of its cross-cultural adaptation to Brazil.

It is noteworthy that validation studies for assessment instruments on the phenomenon of burden regarding the specific population of informal caregivers for dependent elderly within Brazilian culture are unknown, which therefore implies the need for an adequate tool to be applied to this group.

In this manner, this study aimed to perform the cross-cultural adaptation of the CRA instrument for use in Brazil with informal caregivers for dependent elderly, and to assess the content validity of the Brazilian version.

METHOD

A methodological study, with the aim to perform the cross-cultural adaptation of the CRA for use in Brazil with informal caregivers for dependent elderly. The authors of the instrument contacted, Prof. Nurse. PhD. Barbara Given, via e-mail, who granted permission for its use in this study. The original version was made available by the Department of Family Medicine at Michigan State University.

The conducted cross-cultural adaptation process followed recommendations made by specific theoretical framework\(^24\) consisting of five stages with implementation procedures as described below.

1ST STAGE: INITIAL TRANSLATION

Two translators independently performed the CRA’s initial translation from English to Brazilian Portuguese: a Brazilian nurse with a Master’s Degree in Nursing and experienced in university teaching in the elderly health area with proven proficiency in the English language (clinical translator),\(^25\) and a lawyer, public servant, also proficient in the instrument’s main language, but without any experience in issues relating to elderly health (general/neutral translator).\(^26\) The latter, unlike the first translator, was not informed about the construct approached of the instrument or the aim of the translation\(^27\).

2ND STAGE: TRANSLATION SYNTHESIS

The two independently generated initial translations from the previous step (T1 and T2), were then synthesized into a single version (T12),\(^28\) after careful analysis of the two translated versions and the original version of the instrument. For this, an author of the study, under the supervision of a PhD in Nursing with English language skills and experienced in issues relating to elderly health, mediated the translation differences from the original two translators who had analyzed the proposal for a summary version via e-mail. After two “rounds” of evaluation, all translation differences were resolved to get full agreement from the translators on a definitive version of the CRA synthesis tool in Brazilian Portuguese (T12).

3RD STAGE: RETRO-TRANSLATION

T12 version was translated back into English by two bilingual translators (retro translators) to verify whether each item of the Portuguese version accurately reflected the content of the items of the original version\(^27\). The retro translators were: one student, native of the United States of America (USA), resident in Brazil for three years, and one economist, professional translator with dual nationality, born in Brazil, and USA resident for over 20 years. Neither had training or familiarity with issues relating to elderly health, nor did they have access to the original version of the instrument and they also were not informed of the concepts covered by the same\(^27\). The two were initially contacted in person, with a formal request to retro translate and the agreement terms to conclude the work. Later, contact occurred through email. At the end of this step, we obtained two independently produced retro-translations of the instrument (RT1 and RT2)\(^27\).

4TH STAGE: JUDGE COMMITTEE EVALUATION

All versions of the instrument existing at these points: original, T1, T2, T12, RT1 and RT2, were then carefully
examined by a committee of judges, for its semantic, idiomatic, experimental and conceptual equivalencies, in order to establish a pre-version Brazilian CRA, culturally equivalent to the original version. It was up to the judges to make decisions relating to all components of the instrument: items, instructions and answer format(17).

In addition to the two initial translators, the committee of this study was composed of a mediator of translation synthesis and retro translators: A PhD in Nursing, with experience in cross-cultural adaptation and validation of measuring instruments proven by publication of scientific papers (a specialist in the method)(17); an English teacher with 45 years of experience in the position, graduated in English, Portuguese and Literature, with previous experience of residing in a native English speaking country (language specialist)(17); and three nurses, experts in elderly health (care, teaching or research), with mastery in the English language, one with resident experience in the USA, being the country of origin of the rated instrument (health professionals)(17). Therefore the judge committee totaled 10 members.

Each member received a set of documents via email consisting of: letter of invitation, Informed and Clear Consent (ICC) form, translation and cultural adaptation flowchart, informative text about the phenomenon of burden in informal caregivers of dependent elderly, the CRA instrument, a form of identification and professional characterization, a tool for evaluation of the semantic, idiomatic, experimental and conceptual instrument to be adapted, as well as a framework bringing together all versions of existing instrument (original version, T1, T2, T12 , RT1 and RT2)(17).

The judges reviewed the material via e-mail and individually performed the proposed trial. After all the judges answered with their analyses, their suggestions for adjustment of the instrument accompanied by their justifications were pooled together and returned to the group members for consideration, in order to obtain consensus on the judgment of the evaluated equivalencies. A new deadline for response was agreed on, and after two rounds of review by the committee, all discrepancies were resolved, thus resulting in the Brazilian pre-final version of the CRA instrument to be employed in the field for the next step, the pre-test(17).

5TH STAGE: PRE-TEST

In order to check the understanding of the instrument under consideration by the destination country of the target population, there was the pre-test of the pre-final version of the CRA approved in the previous step by the judge committee, along with 30 informal caregivers of dependent elderly residents in the city of Fortaleza(17), contacted through home visits.

From the recommendation of the professional teams of the Family Healthcare Strategy (ESF – in Portuguese) of a Primary Healthcare Unit (UAPs – in Portuguese) in Fortaleza, micro areas of their operating territories where informal caregivers of dependent elderly people with diverse attributes lived were covered, especially with respect to socioeconomic and educational characteristics. This policy was adopted to ensure that the various strata of the study population were covered.

Caregivers answered a questionnaire regarding sociodemographic characterization and information concerning their provision of care to the elderly; we used the Katz and Lawton scales to assess the level of independence of elderly care in the performance of Basic Activities of Daily Living (BADL) and of Advanced Activities of Daily Living (AADL)(18), the pre-final version of the CRA instrument (self-administered, except for illiterate caregivers), and closed questions about their understanding as to each of the items, made with simple and direct language. In the case of items judged to be insufficiently clear, caregivers were asked to suggest changes.

CONTENT VALIDATION

Upon completion of the five stage cross-cultural adaptation process, the Brazilian version of the CRA assessed its content validity with a group of five experts in Elderly Health, recruited from non-probability snowballing sampling, a useful technique for samples whose individuals are difficult to identify(19). For the definition of professional expert, we employed a proposal to identify experts in Nursing(20) with modifications.

From the judgment of the experts as to each item of the final Brazilian version of the CRA, we proceeded to calculate the Content Validity Index (CVI) of the instrument through three mathematical equations: SCVIAve (content validity index average for all items in a scale), SCVI/UA (proportion of items in a scale that achieved scores 3 (relevant) or 4 (very important) by all evaluators), and I-CVI (content validity of individual items)(21).

The study was conducted from February to October 2013 in the city of Fortaleza, Brazil. Data of 1st – 4th stages of cross-cultural adaptation of the CRA instrument for the Brazilian context were organized in tables and analyzed descriptively. 5th Stage data (pre-test) were compiled in the spreadsheet software Statistical Package for Social Sciences (SPSS), version 18.0, and subjected to descriptive statistical analysis. The data for the analysis of the content validity of the Brazilian version of the CRA were organized using Microsoft Excel 2010 and descriptively analyzed.

ETHICAL ASPECTS

The design of this study was previously submitted and approved by the Ethics Committee of the Federal University of Ceará, under protocol No. 339782/2013. The study was conducted in accordance with all ethical standards for research involving human subjects. Participants of 1st to 5th stages of the translation and cultural adaptation process, as well as experts in gerontology and geriatrics responsible for analyzing the content validity of the Brazilian version of the CRA were duly informed about the study objectives and signed the ICC, unlike the participants in 3rd stage of the cross-cultural adaptation (retro-translation), who were service providers.

RESULTS

Both versions produced in the first stage of cross-cultural adaptation of the CRA to Brazil (T1 and T2) showed no
significant differences in translation. However, there were existing subtle distinctions facilitated decision-making on a summary version, which confirms that the translations were complementary: while the T2 version (general translator) was more literal and formal, reflecting the neutrality of the translator and therefore more accurate to the original version, the T1 (clinical translator) version resulted in more informal, more simple and direct language, and therefore more appropriate to the target audience.

For the construction of the synthesis version of the original translations (T12), there were both semantic construction as to the clarity of words and their correspondence with the original version. Two rounds of assessment were required for full compliance on the T12 version.

As for the retro-translation stage of the T12 version, we were concerned with the recruitment, and meeting of people with a broad field of North American English, preferably native USA (home country of the CRA), paying attention to the peculiarities that the English language takes in countries that have it as its mother tongue. This approach seems to be relevant, since the RT1 and RT2 produced versions resulted in similar versions to the original version of the instrument.

In the fourth stage of cultural adaptation, the semantic, idiomatic, experimental and conceptual equivalencies of the CRA in Brazilian Portuguese were evaluated by a committee of 10 judges in relation to its original version, including participants of the previous stages of the undertaken process. The execution took place via e-mail, since in-person meetings were not possible due to large geographical barriers (the judges were in different Brazilian states and countries).

In the first evaluation by the committee, most of the items (17) achieved full agreement from the ten judges (100%) for the four evaluated equivalencies. For the other seven items of the instrument, as well as for the statement response instruction to items, some members of the group identified the need for modifications. The judges suggested adjustments to rewrite the seven items in question mainly related to its semantic equivalence.

The changes suggested by the judges accompanied by their justification, when present, were pooled and sent via e-mail to all members of the group for further evaluation. After two rounds of review by the committee, we reached consensus on the equivalence of the CRA in Brazilian Portuguese with its original version (to reach the pre-final version): two items went back to the original format (T12), and five items along with the instructions that set out to answer the items were modified.

In the last stage (pre-test), the CRA version approved by the judging committee was applied to the 30 informal caregivers of dependent elderly who were living in suburbs of the city of Fortaleza-CE. The approximate time to answer the instrument when self-administered was ten minutes, with an increase of about five minutes when answered during interview (the items were read by the interviewer, in the case of illiterate caregivers).

The general profile of informal caregivers who participated in this stage of the study was: women (96.7%), over 50 years of age (63.3%), with schooling between one and four years of education (36.7%), married or in a consensual union (40%), not currently employed (70%), with no personal income (50%), daughters of the elderly needing care (66.7%), living in the same household as the elderly (93.3%), caring for them for between ten and fifteen years (53.4%), taking care of highly dependent elderly (26.7% dependent for all BADL; 87.5% with a minimum score in the AADL assessment).

A characteristic of caregivers which also stood out was that both education extremes were considered in the pre-test (caregivers who had never studied: 10%; caregivers with 16 years of education: 6.7%).

Items in the CRA pre-final version in the assessment of caregivers were clear and readily understandable with clear and easily eligible answering options. Only three items (8, 12, 18) were considered insufficiently understandable by caregivers, indicating that they needed adjustments. Some participants gave suggestions for rewriting such items. Table 1 shows the percentages of agreement on the understanding, clarity and ease of choice of answers, of non-response, as well as suggestions for rewriting items judged insufficiently understandable by caregivers.

<table>
<thead>
<tr>
<th>Item</th>
<th>Percentage of agreement on item comprehension</th>
<th>Percentage of agreement on clarity and ease of answer choices</th>
<th>Non-response percentage per item</th>
<th>Caregivers suggestions for rewriting the item</th>
</tr>
</thead>
</table>
| 8. I have to stop in the middle of work | 50% | 66.7% | 26.7% | - “I need to stop in the middle of my activities that I was doing to care (for the elderly) "  
| | | | | - “I have to interrupt my other activities to care (for the elderly)” |
| 12. I’d never be able to give back to (him/her) by taking care of him/her | 63.3% | 73.3% | 20% | --- |
| 18. Constant interruptions make it difficult to find time to relax | 76.7% | 80% | 0% | - “The constant demands make it difficult to find time to relax”  
| | | | | - “The constant care demands make it difficult to find time to rest” |
Some caregivers also suggested a change in the positioning of response instructions to the items: these should be submitted at the beginning of the instrument before having access to items, unlike in the original version and the T12 version, in which they were located at the end of the instrument, making it difficult to understand since it is self-administered.

It is noteworthy that all the suggestions of informal caregivers as to the items that were insufficiently understood (8, 12 and 18), as well as the suggestion to reposition the response instructions to the instrument, were pooled and sent via email to all expert panel members from the previous stage of the study for evaluation. However, this last trial occurred with the participation of only six judges in the established deadline for return.

The judges were unanimous in pointing out the relevance of the caregivers’ suggestion to reposition the instrument’s response instructions. In addition, the three study items (8, 12, 18) were modified. We could also observe that in order to make the necessary adjustments, the judges were concerned to preserve the meaning of words of the original version as much as possible, adjusting them to the caregivers’ suggestions.

After approval of the changes by the judges, the Brazilian Portuguese version of the CRA instrument (now with the modified items) was again applied to the three informal caregivers of dependent elderly included in the pre-test (10% of the total employed sample). This time, we found that none of the items aroused any doubt or difficulty in understanding the electing of responses in the opinion of the caregivers, indicating that the adjustments made were satisfactory. This eventually resulted in the Brazilian version CRA instrument for assessing the burden of informal caregivers of dependent older adults (Table 1).

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**Table 1 – Final version of the Brazilian Portuguese CRA instrument for assessing the burden of informal caregivers of dependent elderly - Fortaleza, Brazil, in 2013**

<table>
<thead>
<tr>
<th>Items</th>
<th>I totally disagree</th>
<th>I disagree</th>
<th>I neither agree nor disagree</th>
<th>I agree</th>
<th>I totally agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel privileged to take care of ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Others put the responsibility of caring for ___ on me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. *My financial resources are sufficient to pay for the cost of care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. My activities revolve around caring for ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Since I started taking care of ___, I seem to be tired all the time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. It is very difficult to get help from my family to take care of ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. *I feel resentful for having to take care of ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. I have to stop in the middle of my activities to care for ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. I really want to take care of ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. My health has worsened since I started taking care of ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. I visit my family and friends less since I started taking care of ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Even by taking care of ___, I’d never be able to repay what he/she has done for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. *My family cooperates in the care of ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I have failed to fulfill my commitments since I started taking care of ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. *I am physically strong enough to take care of ___.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Since I started taking care of ___, I feel abandoned by my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. Caring for __ makes me feel good.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. It is difficult to find time to rest because of the constant interruptions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

continued...
It is noteworthy that this version has been translated from Brazilian Portuguese into English and sent via e-mail to the Department of Family Medicine at Michigan State University, along with information about major changes made during the adaptation process carried out for consideration by the authors of the original version. According to their opinion, the modifications undertaken to obtain the Brazilian version of the CRA did not change the meaning of the original version, confirming its complete equivalence and its suitability for the new cultural context, and reflecting the quality of the cross-cultural adaptation process conducted.

Next, we proceeded to review the content validity of the Brazilian version CRA by five experts in the same area as the framework of the instrument (Elderly Health). The CVI results were satisfactory: the S-CVI/Ave (average content validation indices for all items on the scale) was 0.95; S-CVI/UA (ratio of scale items that reached three or four scores by all evaluators) was 0.75; I-CVI (validity of the content items of the individual) was 0.80 or 1 for each of the 24 items of the instrument. Therefore, the value of the CVI resulting from the average of the three equations (SVI-Ave SCVI/UA, I-CVI) was 0.883.

DISCUSSION

It is known that although there is no existing consensus on how to adapt an instrument for use in another cultural environment(22), it is necessary to use methods to ensure the quality of adaptation conducted. In this sense, and in this study, all the recommendations of the theoretical and methodological framework used(13) in relation to the five steps recommended were performed with austerity.

Cross-cultural adaptation studies of measurement instruments are often arduous and time-consuming. In conducting this research, certain routines were relevant to its timely completion, such as the pre-planning of the execution of each of the stages, including early identification of likely collaborators, as well as the schedule of personal meetings with members of the 1st, 3rd and 4th stages to conduct formal invitations to participate. This seemed to have facilitated the accession of the collaborators to compromise with the deadlines for responding to requests.

It can be said that the pre-test stage was of great importance in the establishment of the Brazilian version CRA, in that it reflected the suitability of the instrument to its target audience. The implementation of the pre-final version together with the informal caregivers of elderly revealed potential details of confusion regarding the understanding and interpretation of three items of the instrument. However, it needed only minor adjustments, especially with regard to cultural correspondence and semantic structure of sentences.

The re-evaluation by the judge committee of insufficiently understood items by caregivers during the pre-test stage, and the suggestions offered by the target subjects for changes in the sentences was relevant in the judges’ opinions, because it more strictly adhered to ensuring its equivalence to the original version in obtaining the final version of the adapted instrument.

In the context of finalizing the process, it should be noted that the submission of the final Brazilian version of the instrument to the authors of the original version was a particularly relevant procedure, as it confirmed the equivalence of the tool to the new cultural context, based on the opinions of those responsible for development of the primary version, ensuring that the undertaken process was well conducted because the resulting instrument preserved the same direction of its original version.

Moreover, the result obtained by calculating the CVI (0.883) revealed that the Brazilian version CRA instrument has valid content(21) for assessing the burden of informal caregivers of dependent elderly in this country.

CONCLUSION

The theoretical and methodological framework used in this study was satisfactory, in that it assured obtaining an instrument that after being adapted to the Brazilian culture it has proved to be semantically, idiomatically, experimentally and conceptually equivalent to the original version, which
enables us to conclude the credibility and consistency of the cross-cultural adaptation process tool.

The Brazilian version CRA showed a simple and quick application (about ten minutes), being easily understandable by the target audience. Moreover, it was found that the CVI obtained from the analysis of professional experts in the Elderly Health area provides evidence of the validity of its contents for assessing the burden of informal caregivers of dependent elderly Brazilians.

We suggest to adapt measurement tools for other cultures as a recommendation for future research, and in addition to the effectiveness of cross-cultural adaptation process, the final version obtained should be sent to the authors of the original tool, in order to confirm its equivalency as quality assurance for the undertaken process.

Despite the austerity with which the cross-cultural adaptation of the CRA for use in Brazil was conducted and the confirmation of its content validity, it is necessary that its other psychometric measures of validity and reliability are analyzed and confirmed in order to enable the instrument to be used in assessing the burden of informal caregivers of dependent elderly Brazilians, both in care practice and in scientific research.


