Original Article

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Sense of mastery in caregivers of people living with dementia:
translation and cultural adaptation of the *Pearlin Mastery Scale*

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ABSTRACT. The sense of mastery is conceptualized as a positive aspect of care targeted at people living with dementia, a coping mechanism to reduce burden, and may represent a protective factor for caregivers' mental and physical health. **Objective:** To translate and culturally adapt the *Pearlin Mastery Scale* for Brazil. **Methods:** A methodological study was conducted at the Federal University of São Carlos in which the initial translation stages were followed; synthesis; back-translation; review by the committee of judges by analyzing the Content Validity Index (CVI); and test of the pre-final version. **Results:** Two specialists translated the scale into Brazilian Portuguese and defined a consensus version with the researchers. Subsequently, another two specialists back-translated the consensus version, which was reviewed by three judges who are PhDs in the area, considering all scale items as very equivalent (CVI=1.0), and maintaining them in the pre-final version of the instrument. This was tested in a first group of caregivers for them to point out adjustments. The suggestions were accepted by modifying three items and, afterward, the scale was tested in a second group, which did not present difficulties answering the instrument. **Conclusion:** The *Pearlin Mastery Scale* was translated and culturally adapted for Brazil, showing equivalence. However, future psychometric analyses of the instrument are required to make it available for use in this population.

Keywords: Dementia; Caregivers; Methods; Psychological Adaptation.

Senso de domínio de cuidadores de pessoas que vivem com demência: tradução e adaptação cultural da *Pearlin Mastery Scale*

RESUMO. O senso de domínio é conceituado como um aspecto positivo do cuidado voltado às pessoas que vivem com demência, um mecanismo de enfrentamento para reduzir a sobrecarga e que pode representar um fator protetor para a saúde mental e física do cuidador. **Objetivo:** Traduzir e adaptar culturalmente a *Pearlin Mastery Scale* para o Brasil. **Métodos:** Estudo metodológico conduzido na Universidade Federal de São Carlos, em que foram seguidas as etapas de tradução inicial; síntese; retrotradução; revisão pelo comitê de juízes pela análise do Índice de Validade de Conteúdo (IVC); e teste da versão pré-final. **Resultados:** Dois especialistas traduziram a escala para o português brasileiro e definiram uma versão consensual com os pesquisadores. Posteriormente, outros dois especialistas retrotraduziram a versão consensual, que foi revisada por três juízes doutores na área, considerando todos os itens da escala como muito equivalentes (IVC=1,0), mantendo-os na versão pré-final do instrumento. Esta foi testada em um primeiro grupo de cuidadores, a fim de se apontarem adequações. As sugestões foram acatadas mediante a modificação de três itens e, depois, a escala foi testada em um segundo grupo, o qual não apresentou dificuldades em responder ao instrumento. **Conclusão:** A *Pearlin Mastery Scale* foi traduzida e adaptada culturalmente para o Brasil, demonstrando equivalência. Entretanto, análises psicométricas futuras do instrumento são necessárias para disponibilizá-lo para uso entre essa população.

Palavras-chave: Demência; Cuidadores; Métodos; Adaptação Psicológica.

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INTRODUCTION

Globally, the population is aging rapidly, affecting all levels of society[1]. With advancing age, people become susceptible to developing chronic conditions, as well as functional, and cognitive and sensory losses[2]. In this context, dementia represents one of the main causes of disability during aging[3]. Data from the World Health Organization (WHO) indicate that, in 2019, 55.2 million people lived with dementia worldwide and it is estimated that the condition will affect 78 million people in 2030 and nearly 139 million by 2050[4].

In addition to the enormous impact on the affected individuals, economy, and society, dementia exerts a significant impact on family members, who represent the main source of the care provided to these people, especially in low- and middle-income countries[5]. Having the knowledge about dementia and mastery over its care is essential so that caregivers do not pose risks to the people cared for, increasing their quality of life and helping themselves to face the disease[6].

In this way, the sense of mastery is conceptualized as a positive aspect of care, a coping mechanism to reduce burden, a conviction that an individual is capable of controlling the important circumstances that affect her/his life, and can represent a protective factor for mental and physical health and well-being, especially when facing persistent life stresses such as economic and occupational difficulties[7-9]. In view of this, caregivers' mastery of care is oftentimes neglected, and the absence of training and information about dementia and its consequences are considered the main difficulties faced by them[10].

Caregivers of people living with dementia can develop a sense of mastery and purpose of the care tasks and activities, reflecting gains in positive aspects during this experience[9]. In general, they report that the activity can improve the perception of personal growth from positive experiences (gains), meanings (spiritual attributions), rewards, and benefits[11]. Thus, positive aspects such as the caregivers' sense of mastery can be important protective factors that can mediate the effects of burden[12,13].

In this context, the *Pearlin Mastery Scale* (PMS) was originally developed by Pearlin and Schooler in the 1970s for a study on stress and coping with a sample comprised of 2,300 men and women of working age (18–65 years old) who lived in the urban area of Chicago, as the population should be weighted in favor of those who were actively involved in different professional categories[7]. Since then, the scale has been used to study the role of the sense of mastery in managing chronic metabolic, rheumatic, and cardiovascular diseases[14]. The instrument measures an individual's mastery level through seven items (five negatively worded and two positively worded), scored on a Likert scale with 1 to 4 options for each answer (reverse coding for both positively worded items), with a total score varying between 7 and 28 points, where higher scores indicate greater mastery levels. The instrument showed acceptable reliability to be used among the family caregivers of dependent older adults (ω=0.80)[13].

Despite the research studies carried out on the use of PMS in the United States, Europe, and Asia, the sense of mastery is still little known in Brazil and there is no version of the instrument for the Brazilian context[13,14]. In view of the above, the availability of the translated and culturally adapted scale for use throughout the country is important and necessary to evaluate the effectiveness of interventions as well as training programs focusing on caregivers of people living with dementia. Therefore, the study aimed at translating and culturally adapting the PMS with informal caregivers of people living with dementia in the Brazilian context.

METHODS

This is a methodological study proposing the translation and cultural adaptation of the instrument called *Pearlin Mastery Scale* for the Brazilian context. For the adaptation process, the stages recommended by Guillemin, Bombardier and Beaton[15] were sequentially followed, namely: first translation (through independent translators); summary of the translations (establishment of a single version of the scale through consensus determined by those involved — translators and researchers); back-translation (translation of the consensual version of the scale in the Brazilian version into American English by two lay translators as to the objectives of the study, who are native speakers of the second language); determination through the commissioning of three judges fluent in the native language of the scale, PhDs in the health area and with experience with informal caregivers of people living with dementia and on the theme of cultural adaptation of instruments; and testing of the pre-final version.

Following the stages recommended by the theoretical framework adopted, PMS was translated from American English to Brazilian Portuguese by two specialized bilingual translators, who thereafter formulated a consensus version. The reliability of this version was assessed through back-translation into American English, which was carried out independently and blindly by another competent translator, whose native language was American English and had experience in translating

texts for the health area. The translator was not familiar with the original version of the scale used or the objectives of the current study. Thus, the PMS consensus version in Brazilian Portuguese and the back-translated version were measured by a committee of judges comprised of three specialists. The criteria for committee composition were based on being trained in the health area, fluent in the English language, an expert on the topic of caregivers, as well as having methodological knowledge of the research used, in other words, having practice in translations and adaptations of instruments.

After agreeing to participate in the study by signing the Free and Informed Consent Form (FICF), the judges had access to the documents for evaluation and an explanatory letter regarding the study objectives. In addition, they received details about the scale, taking into account cultural equivalence between the original and final versions, following the rationale proposed by Guillemin, Bombardier and Beaton[15], which establishes the following aspects of equivalence: semantic, idiomatic, experimental or cultural, and conceptual.

To analyze the data from the experts' committee, a descriptive analysis was performed, besides content validity using the Content Validity Index (CVI), which indicates the proportion of experts who agree on certain aspects of the instrument and its items, allowing for an individual analysis of the items at a first moment and, subsequently, of the instrument as a whole[16]. The judges' assessment instrument consisted of a Likert-type answer scale between 1 and 4 points, where the specialists could consider for each item of the scale: 1=Not equivalent; 2=Little equivalent; 3=Equivalent; and 4=Very equivalent. In order to interpret the CVI, the criterion proposed in the literature was used, which recommends a value above 0.78[17]. CVI scores were calculated by summing the agreement of the items evaluated between 3 and 4 by the specialists, divided by the total number of answers.

The suggestions made by the experts' committee, pertinent to language adaptation and better understanding by the responding individuals, were expressed through an evaluation table. To test the pre-final version, the instrument was applied to some of the research participants through online and individual interviews, aiming to detect errors and confirm understanding of all the questions. In this study, it was decided to use the test technique, applying the instrument to two groups of informal caregivers of people living with dementia to verify the clarity of the content and difficulty understanding the scale items, as well as to identify possible errors. The objective of dividing the participants into two groups was to gather notes from the first group and improve the writing of items for better understanding by the second group. Before fully answering the questionnaire, the participants should agree to participate in the study by signing the FICF.

The study complies with Resolution 510/16 of the National Health Council (*Conselho Nacional de Saúde*, CNS), which guarantees rights to the research participants, the scientific community and the State. Therefore, it was assessed and approved by the Research Ethics Committee of the Federal University of São Carlos (Opinion No. 5.332.333; CAAE nº 88157118.0.1001.5504). All ethical procedures for research in human beings were respected.

RESULTS

Initially, PMS was independently translated from American English to Brazilian Portuguese by two qualified bilingual translators, who defined a consensus PMS Brazilian Portuguese version, assessing existing differences in the translations and considering the original version of the scale. The reliability of the consensus version was evaluated through back-translation into English by another qualified translator and presented similarities with the original instrument. Subsequently, the consensus and back-translated versions were evaluated by the committee of judges, who signed a unanimous agreement, without divergence, on 88.8% of the items in the consensus version. For the last item, changes were suggested to ease understanding, as demonstrated in Supplementary Material, Chart 1.

After the evaluation by the committee of judges, it was verified that all the items that made up the PMS presented CVI=1.0, being considered equivalent and maintained in the pre-final version of the instrument, as shown in Supplementary Material, Chart 2.

For the pre-test of the version approved by the judges, PMS was applied individually in the online interview format to a sample consisting of two groups of caregivers of people living with dementia to verify clarity and understanding of the items. Seven caregivers participated in the pre-test: four in the first group and three in the second. Of the sample, 57.1% were female, with a mean age of 55.2 years, and living in different regions of the country. The caregivers' characteristics can be seen in Supplementary Material, Chart 3.

Among the participants in the first group, 75% asserted that the questions were clear enough, rating the scale as good. However, one participant pointed out occasional comprehension difficulties in questions 1, 6, and 7, which led the researchers to exclude the term "*realmente*" ("really") from question 1 and include the

expression "*a forma de lidar com*" ("how to deal with") at the beginning of question 6, for greater understanding and clarity of the items. In addition, there was a word order change in question 7 to improve the meaning of the sentence. Supplementary Material, Chart 4, shows the changes implemented by the researchers in each item according to the suggestions.

After making the adjustments pointed out by the first group of caregivers, the last version of the scale was applied to the participants of the second group, who did not present difficulties answering the items. The final PMS version is presented in Supplementary Material, Chart 5.

DISCUSSION

The PMS has been translated and culturally adapted for the Brazilian context (now called *Escala Pearlin de Domínio*), bridging the existing gap in the assessment of the sense of mastery in caregivers of people living with dementia in Brazil. For adaptation processes, it is recommended in the literature that some steps be adopted, thus contributing significantly to the quality of the results, which sees the Portuguese version of the instrument faithful to the linguistic content of the questionnaire in the original language (English). Through this confirmation, suitability is achieved for unanimous content validation by the experts' committee, ensuring that the scale is clear and understandable in the new culture.

With the PMS in Portuguese ready, a pre-test was carried out to be applied to a sample of caregivers of people living with dementia and to verify whether they would encounter any difficulties related to understanding and clarity of the instrument items. In the current study, the suggestions made by the first group of participants were accepted and the second group did not report difficulties or suggest changes, thus obtaining the final version of the scale.

Some tools are developed in a specific language and then go through a translation process into a desired language. The panel of experts is extremely important when it comes to validating scales and questionnaires regarding cultural and linguistic adaptation. This is a rigorous procedure due to the particularities of the countries involved. In this sense, if the methodological quality of instrument selection is poor, this may be considered a bias in the study's conclusions[18]. The analysis of the psychometric properties of the PMS Spanish version, conducted with two groups of patients diagnosed with cancer or type II diabetes, verified that the instrument may not consistently measure mastery between the groups[14]. This is possibly due to differences in semantic understanding of items by the respondents or to differences in the meaning of the construct itself, emphasizing the importance of adequate validation by a committee of judges during the methodological process of translation and cultural adaptation[14].

In Singapore, the PMS translation and psychometric analysis study was conducted with family caregivers of dependent older adults. The data of the seven-item scale showed acceptable reliability, although they reflected poor fit for both positively worded items. Without these two items, the answers in the five-item version showed acceptable model fit and had superior reliability and high correlation with those in the seven-item version[13]. This finding corroborates the study that analyzed the PMS Japanese version using the seven- and five-item versions of the instrument, which evidenced superior reliability for the reduced version of the scale[19].

The Chinese version of the scale was translated and culturally adapted with a sample consisting of three groups of patients diagnosed with major depression, schizophrenia, and HIV/AIDS, respectively. In addition to content validity, the scale presented acceptable psychometric qualities in terms of reliability, classification performance, and characteristics of the items when applied to different groups[8].

In general, there is a large body of literature examining the impact of interventions on care variables that focus on adverse results such as burden, depression, and anxiety[20,21]. Meanwhile, positive aspects of caring for people living with dementia, such as a sense of mastery, should be investigated, as they provide a different perspective on how the interventions have made a difference in the caregivers' lives[22]. However, the sense of mastery is still little known in Brazil and, although many research studies on validation and use of the PMS have been conducted in other countries[8,14,19], no Brazilian version has yet been developed. National and international studies revealed the need to provide the Brazilian population with a sense of mastery screening instrument, given the scarcity of studies related to this variable and the need to recognize coping strategies that may assist caregivers of people living with dementia, encouraging the development of policies and resources that meet the search for better care quality[22,23].

As a limitation, we can highlight the scarcity of studies carried out in Brazil on this theme, making it difficult to deepen the discussion. As a perspective for future studies, performing psychometric analyses of the scale, taking into account the necessary adjustments for both positively formulated items, will make it possible to provide a reliable instrument for use in intervention research studies.

The PMS (now called *Escala Pearlin de Domínio*) was translated and culturally adapted for informal caregivers of people living with dementia in Brazil. This result enables and enhances comparisons of data on the variable with global findings. Additionally, it allows health professionals who meet the care demand for people living with dementia in different health contexts to have a quick screening scale as a tool on a positive aspect of care, such as the sense of mastery, allowing them to improve such coping strategy.

AUTHORS' CONTRIBUTIONS

GCB: conceptualization, data curation, formal analysis, investigation, methodology, writing – original draft, writing – review & editing. ACO: formal analysis, investigation, methodology, project administration, supervision. DQM: formal analysis, investigation, methodology, project administration, supervision. CRFC: formal analysis, investigation, methodology, project administration, supervision. KCTC: project administration, supervision. LCSA: data curation, formal analysis, investigation, methodology. LC: data curation, formal analysis, investigation, methodology. LAR: data curation, formal analysis, investigation, methodology. GM: formal analysis, investigation, methodology. BRSM: formal analysis, investigation, methodology. EJB: formal analysis, investigation, project administration, supervision. SCIP: formal analysis, investigation, project administration, supervision. FSO: formal analysis, investigation, project administration, supervision. ACMG: conceptualization, data curation, formal analysis, investigation, methodology, writing – original draft, writing – review & editing.

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