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Adaptação Transcultural do Marwit-Meuser Caregiver Grief Inventory/Short form para cultura brasileira

Cross-cultural adaptation of the Marwit-Meuser Caregiver Grief Inventory/Short form for Brazilian culture

Emanuela Bezerra Torres Mattos
Federal University of São Paulo
https://orcid.org/0000-0002-1780-2355
emattos@unifesp.br

Jéssica Paloma Santos Oliveira
Federal University of São Paulo
https://orcid.org/0000-0002-3902-5016

Luana de Souza Castro
Federal University of São Paulo
https://orcid.org/0000-0001-7205-2940

Marcia Maria Pires Camargo Novelli
Federal University of São Paulo
https://orcid.org/0000-0002-2058-4950

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Deusivania Vieira da Silva Falcão
University of São Paulo
https://orcid.org/0000-0001-6839-4606

Thomas Meuser
University of New England
https://orcid.org/0000-0003-1970-1651

Resumo

Introdução: O Marwit-Meuser Caregiver Grief Inventory (MM-CGI) é um inventário que avalia o luto em cuidadores de pessoas com demência que é uma experiência pouco explorada no contexto brasileiro. **Objetivo**: Adaptar transculturalmente o MM- CGI/Short Form para uso no Brasil. **Materiais e Método:** Realizou-se uma tradução inicial; síntese das traduções; avaliação desta síntese pelo comitê de juízes experts para analisar a validade aparente e de conteúdo, avaliação pelo público-alvo e a tradução reversa. **Resultados**: A versão única compilada em 60 itens foi avaliada pelos juízes experts. A versão final pelo público-alvo com cuidadores familiares (n=7) e o estudo piloto com 86 cuidadores familiares. As análises da consistência interna indicaram coeficientes alfa 0,84; 0,81; 0,76, para os domínios A, B e C. **Considerações Finais**: O estudo disponibiliza a versão brasileira deste instrumento que passou a se chamar em português Inventário de Luto do Cuidador de Marwit-Meuser/Versão Reduzida.

Palavras-chave: Luto; Luto antecipatório; Cuidador; Demência.

Abstract

Introduction: *The Marwit-Meuuser Caregiver Grief Inventory (MM-CGI) is an inventory that assesses grief in caregivers of people with dementia, which is an experience little explored in the Brazilian context.* ***Objective:*** *Cross-culturally adapt the MM-CGI/Short Form for use in Brazil.* ***Material and Method:*** *An initial translation was performed; synthesis of translations; evaluation of this synthesis by the committee of expert judges to analyze the face and content validity, evaluation by the target audience and the back translation.* ***Results:*** *The single version compiled into 60 items was evaluated by expert judges. The final version by the target audience with family caregivers (n=7) and the pilot study with 86 family caregivers. Internal consistency analyzes indicated alpha coefficients of 0.84; 0.81; 0.76, for domains A, B and C.* ***Final Considerations:*** *The study provides the Brazilian version of this instrument, which is now called Marwit-Meuser's Caregiver Grief Inventory/Short Form.*

Keywords: *Grief; Anticipatory grief; Caregiver; Dementia.*

Resumen

Introducción: *El Marwit-Meuser Caregiver Grief Inventory (MM-CGI) es un inventario que evalúa el duelo en cuidadores de personas con demencia, experiência poco explorada en el contexto brasileño.* ***Objetivo:*** *Adaptar transculturalmente el MM- CGI/Forma corta para su uso en Brasil.* ***Material e Método:*** *Se realizó una traducción inicial; síntesis de traducciones; evaluación de esta síntesis por el comité de jueces expertos para analizar la validez aparente y de contenido, evaluación por el público objetivo y la retrotraducción.* ***Resultados****: La versión única compilada en 60 ítems fue evaluada por jueces expertos. La versión final por el público objetivo con cuidadores familiares (n=7) y el estudio piloto con 86 cuidadores familiares. Los análisis de consistencia interna indicaron coeficientes alfa de 0,84; 0,81; 0,76, para los dominios A, B y C.* ***Consideraciones finales****: El estudio proporciona la versión brasileña de este instrumento, que pasó a llamarse Inventario de Duelo del Cuidador de Marwit-Meuser/Versión Reducida.*

Palabras llave*: Duelo; Duelo anticipatorio; Cuidador; Demencia*

Introduction

Approximately 60% of people living with dementia reside in low and middle-income countries. Worldwide, cases are expected to count 82 million in 2030 and 152 million in 2050. The annual cost of one trillion dollars today is expected to double by 2030 (Alzheimer's Disease International, 2021).

With the growing prevalence and incidence of dementia, the number of family members who assume a caregiving role will grow exponentially. Family caregivers face many challenges, notably adaptation to the demands that arise as a result of disease progression. Changes in functional performance of the person with dementia which impact life management (i.e., instrumental activities of daily living) and basic self-care (i.e., activities of daily living) create new, potentially harmful, burdens for family caregivers over time. Dependence gradually intensifies as the disease progresses, increasing the need for help and supervision in basic and instrumental activities of daily living by caregivers, reaching an interval of approximately 10 to 12 hours a day and an average of 15 years in that care (Ferreti et al, 2018).

The helping relationship between caregiver and care recipient has different faces and phases that change over time. Challenges increase as dementia severity progresses. Dealing with the decline in cognitive and functional abilities of the person with dementia; offering physical and emotional support; managing day-to-day activities (i.e., medication, organizing finances); managing behavioral changes (i.e., apathy, depression, aggressiveness); among others, can affect the physical and emotional health, quality of life and well-being of the caregiver (Mattos, Oliveira & Novelli, 2020). Perception of deficits as permanent losses foster active grieving in many caregivers (Crawley et al, 2022).

Caregiver grief has been described as a relatively unique, emotionally complex, and multifaceted experience (Blandin & Pepin, 2017). Witnessing the gradual death of a family member's memory and personal identity presents a unique form of mourning associated with losses related to a lost past, present, and anticipated future. For many caregivers, the burden of grief is carried alone, without significant socio-familial recognition or support (Doka, 2004). This phenomenon has been referred to as "double death" because caregivers mourn the loss of the recipient of care before the actual death (Jones & Martinson, 1992). Loss of personal connection and relationship may happen years before bodily death. This situation in dementia is also known as ambiguous loss in which the relative is physically present but psychologically absent (Leidl et al., 2023). In this sense, given the behavioral and role changes of people with dementia, family members commonly experience a conflicting situation, resulting in physical and emotional stress in different degrees. Accepting and, at the same time, avoiding this reality, are the most common strategies used by family members.

In situations involving diseases, such as cancer, in which cognitive functions often remain intact, caregivers and patients have the opportunity to discuss the prospect of death and offer mutual support. This mutually adaptive process of grieving does not happen in dementia because cognitive decline makes it difficult, if not impossible, for patients and caregivers to suffer together. By the time bodily death is near, psychosocial death may be years in the past (Meuser &Marwit, 2001). While grief is a part of universal in nature, the grief in dementia is a relatively unexplored construct in literature despite its undoubted relevance (Meuser &Marwit, 2001; Marwit et al, 2008). Other terms used to describe the concept of caregiver grief include “anticipatory grief” (Rando, 1986), “pre-death grief” (Crawley et al., 2022) and “dementia grief” (Blandin & Pepin, 2017). Validated and culturally adapted instruments to clinically and scientifically assess caregiver grief are essential for targeting and tracking supportive interventions (Rando, 1986).

The Marwit-Meuser Caregiver Grief Inventory (MM-CGI) was the first empirically derived instrument to measure grief in dementia family caregivers (Marwit & Meuser, 2002). The original version consisted of 50 declarative statements on key aspects of grieving derived from sixteen focus groups (Meuser &Marwit, 2001; Marwit & Meuser, 2002). An 18-item short form (MM-CGI-SF) followed and is the most widely used version today (Marwit & Meuser, 2005).

This instrument has already been cross-culturally adapted between Chinese caregivers from Hong Kong, Turkey, the United Kingdom and African caregivers living in the United States (Chan, Wong, Kwok & Ho, 2017; Liew et al, 2018; Ar & Karanci, 2020; Gilsenan, Gorman & Shevelin, 2020; McLennon, Bakas, Habermann & Meuser, 2014).

Objective

Based on this scenario, this research aimed to carry out a cultural adaptation of the MM-CGI-SF for the Brazilian context. More specifically, it aims to describe the stages of translation and cross-cultural adaptation of the instrument's items – a process that precedes the validity evidence studies to be carried out. The choice of cross-cultural adaptation and validation of the MM-CGI-SF, to the detriment of other available instruments in the literature was due to the advantage of evaluating the grief of family caregivers of elderly people with dementia in a single and brief instrument.

Method

Participants

For this step of translation of the MM-CGI-SF, the study had the participation of two fluent translators in the original language (English) and native speakers in the target language (Portuguese). Each translator produced a Portuguese version of the instrument independent of each other.

For the validity stage of content of the MM-CGI-SF five experts participated in a panel comprised of a physical therapist, a psychologist, an occupational therapist specialized in palliative care and bereavement, a psychiatrist and a psychologist specialized in gerontology – all native in Portuguese and fluent in English, with knowledge about the construct to be evaluated by the instrument. At this stage, a pre-test was also carried out with seven selected family caregivers who were participants in the Care Service to Cognitive Aging (SAEC) – an extension program aimed at assisting older people with cognitive impairments at the Federal University of São Paulo (UNIFESP). At this stage, face-to-face data collection was canceled due to the restrictions imposed by the Covid-19 pandemic, which limited the number of participants.

In the pilot study stage, family caregivers of elderly with dementia participated in the research. The inclusion criteria were: a) being Brazilian; b) being a family member and caregiver of a person with dementia; c) not being remunerated for the role of caring; d) having internet access to answer the questionnaire.

Instruments

The MMCGI-SF is an empirically based self-report questionnaire with the objective to measure grief in caregivers of persons with dementia (Marwit & Meuser, 2005). It was based on the the long version (MM-CGI) - of North American origin - proposed by Marwit and Meuser (2002); from elements identified in the literature, including other assessment measures; and through focus groups with family members that are caregivers of persons with dementia in the early, moderate, advanced and after-death stages.

According to the authors, the MM-CGI-SF retains the integrity of the original scale in the sense that it too reliably yields a total grief score as well as sub-scale grief scores representative of the three factors: (1) Personal Sacrifice Burden, (2) Heartfelt Sadness, and (3) Longing, Worry, and Felt Isolation. The resulting correlations of factors 1, 2, and 3 on the MM-CGI-SF with their respective factors 1, 2, and 3 on the MM-CGI were .915, .925, and .928, respectively ($p < .01$) (for more details, see Marwit & Meuser, 2002).

The MM-CGI-SF is a questionnaire composed of 18 self-administered items and a five-point Likert-scale format, ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). The 18 questions addressed in the inventory are divided into subscales classified by factors (1, 2 and 3). Each of the three factors has 6 questions. Personal overload is addressed in domain A (Factor 1), which questions and focuses on the caregiver's losses in the present life related to their role, such as loss of personal freedom (e.g. that is, “I am no longer free to do things for myself”), loss of sleep, compromised health and loss of energy. The feelings of deep sadness and homesickness are addressed in domain B (Factor 2) questions, which express the intrapersonal emotional reactions that accompany the care process (for example, sadness, homesickness, feeling of impotence and denial). This factor seems to be more related to the traditional concept of mourning in the face of emotional reactions to real or imminent losses. Domain C (Factor 3) assesses the concern and feeling of isolation in the face of social disconnection experienced during the care process. At the end of the questions proposed by the inventory, the sum of the scores in each factor 1 (6 items), 2 (6 items) and 3 (6 items) indicates the total level of grief (A + B + C) which may vary from 18 to 90 points.

Procedures and ethical aspects

Initially, the author of the instrument was contacted via e-mail, and authorization was requested to carry out its translation and adaptation to the Brazilian context. The author granted permission. This is a validation study restricted to the stages of cross-cultural adaptation, approved by the Research Ethics Committee of the Federal University of São Paulo through opinion number 4.230.618, under the terms of Resolution 466/2012, of the National Health Council. All participants signed an informed consent form.

The MM-CGI-SF was adapted for the Brazilian culture according to the methodological guidelines accepted and recommended in the scientific literature and synthesized by Borsa, Damásio and Bandeira (2012), namely: 1) translation of the instrument into the new language; 2) synthesis of translated versions; 3) evaluation by experts; 4) evaluation by the target audience; 5) back-translation; and 6) carrying out the pilot study. The details of this process are presented below.

Instrument translation

Translation of the instrument from the original language (English) to the target language (Portuguese). It was performed by two fluent translators in the original language and native speakers in the target language. Each translator produced a Portuguese version of the instrument independent of each other. Translators were asked to avoid local and regional expressions from Brazil that are little known in other countries.

Synthesis of translated versions

Two versions of the instrument translated from English into Brazilian Portuguese were obtained. At this stage, the process of synthesizing the versions began. This was carried out by the researchers responsible for the study translation and cross-cultural adaptation of the instrument in Brazil. The evaluation of the different translations was carried out for each item in particular, evaluating the equivalences between the translated versions and the original one in four different areas, namely: (1) semantics – it checks if the words have the same meaning, if the item has more than one meaning and if there are grammatical errors in the translation; (2) idiomatic – analyzes whether the items of the original instrument were adapted by an equivalent expression that did not change the cultural meaning of the item; (3) contextual – observes whether a given item of an instrument is applicable in the new culture and, if not, replaces it with an equivalent item; (4) conceptual – checks whether a given term or expression, even if properly translated, evaluates the same aspect in different cultures (Borsa, Damásio & Bandeira, 2012).

Evaluation by experts

Evaluation of the first version by five experts in a panel comprised of a physical therapist, a psychologist, an occupational therapist specialized in palliative care and bereavement, a psychiatrist and a psychologist specialized in gerontology – all native in Portuguese and fluent in English. They were asked to review the structure, layout, instrument instructions, scope and adequacy of the expressions contained in the items. Expert panelists considered, for example, whether the terms or expressions could be generalized to different contexts and populations (that is, different regions of the same country) and whether the expressions were suitable for the target audience of the instrument. Aspects of the instrument's layout were analyzed, since these are as essential as the linguistic factors of the items, especially when it comes to instruments for use with specific populations, such as older people. The adequacy of the type and size of the font used, the arrangement of information in the instrument, among others, were analyzed. After translation, synthesis, and evaluation by specialists, the Brazilian Portuguese version of the instrument was obtained, becoming the instrument for the next step.

Evaluation by the target audience (pre-test)

This step aimed to verify if the items, instructions and response scale were understandable to the target audience, considering the semantic, idiomatic, conceptual and cultural equivalences, as well as the appearance of the instrument. It was applied to a target population with seven family caregivers of elderly in the early and moderate stages of Alzheimer's disease. These were recruited from the Care Service to Cognitive Aging (SAEC), which is an extension program aimed at assisting older people with cognitive impairments at the Federal University of São Paulo (UNIFESP) - Baixada Santista Campus. At this stage, face-to-face data collection was canceled due to restrictions imposed by the Covid-19 pandemic, limiting the number of participants. Caregivers answered the adapted inventory and possible discussions emerged to complement the process of adapting the inventory to Brazilian culture.

Caregivers answered the adapted inventory and possible discussions emerged to complement the process of adapting the inventory to Brazilian culture.

Back-translation

After the incorporation of feedback, the revised version was translated from Portuguese into the source language (English) by two native translators. The preliminary version of the MM-CGI-SF was translated into English. A third bilingual, native English-language translator, who did not participate in the first stage of translation, performed this procedure. Then, this version was forwarded and approved by the author of the original instrument. The MM-CGI-SF back-translation procedure was evaluated by the instrument's author and the researchers, aiming to ensure equivalence between the items of the two versions in both cultural contexts.

Pilot study

The application of the instrument in the pilot study required adaptation to the virtual environment in the face of the COVID-19 pandemic. Therefore, publicity was carried out on social networks to reach individuals who met the following inclusion criteria: a) having a Brazilian nationality; b) being a family member and caregiver of a person with dementia; c) not being remunerated for the role of caring. The exclusion criteria were being a professional caregiver. All individuals who expressed interest in collaborating were contacted and received the Informed Consent Form (ICF) made available via Google Forms (they received an original copy signed by the responsible researcher via e-mail), so that they were informed about the objectives of the study, as well as its ethical principles. After accepting, they received the link to complete the Caregiver Grief Inventory of Marwit-Meuser/Short Form.

Data analysis

In the pre-test and pilot study, descriptive statistics with mean and standard deviation were used to assess the caregivers' level of understanding score. Furthermore, in the pilot study, the reliability assessment was carried out through internal consistency, using Cronbach's alpha coefficient (Cronbach, 1996).

To quantify the degree of agreement between experts during the process of evaluating the content validity of the MM-CGI-SF, the percentage of agreement method between experts was based on the following formula (Tilden, Nelson & May, 1990).

$$\%\ \text{agreement} = \frac{\text{Number of experts who agreed X 100}}{\text{Number of experts who did not agree}}$$

During the entire process, an acceptable agreement rate of 80% among experts was considered, that is, among the 5 experts, 4 would have to agree for a certain item to be accepted.

Results

Pre-test

Regarding the level of education of the family caregivers (pre-test), 71% of them had higher education, 14% were graduated and 14% had primary education. Kinship indicated that approximately 71% of the participating caregivers were offspring, 14% mother and 14% wife.

In the translation process, a total of 60 elements (18 scale items and 42 analysis units of instructions and response scale) were identified to be translated. In the translation stage, no conflicting items were identified and the first Portuguese version was produced. These made up the first round of evaluation by the expert judges committee. From this round on, a total of 29 (48.33%) elements in disagreement were computed, that is, they did not reach 80% of agreement among the committee members. Among the 29 elements, 5 had disagreement on semantic equivalence, 12 on idiomatic equivalence, 4 on conceptual equivalence and 8 on cultural equivalence. It is noteworthy that the same item may have disagreement in more than one of the equivalences.

Table 1.
Elements from the first round of evaluation that obtained a percentage of agreement.

Elements/ Items	Synthesized translated version	Changes proposed by the committee	Final version translated and adapted
1	Caregiver grief Inventory/Reduced version	Inclusion of words to facilitate the understanding of the sentence.	Inventário de Luto de Marwit- Meuser /Versão Reduzida.
2	**Instructions:** This inventory is designed to measure the grief experience of current Family caregivers of people living with progressive dementia (e.g. Alzheimer's disease)	Modification of words to make the sentence easier to understand.	**Instruções:** Este inventário foi elaborado para avaliar a experiência de luto de familiares que são, atualmente, cuidadores de pessoas que vivem com demência progressiva (por exemplo, doença de Alzheimer).
4	Circle a number from 1 to 5 to the right using the answer key below (e.g. 5 = completely agree)	Inclusion/exclusion/modification of words to make the sentence easier to understand.	Assinale com um "X" somente um número de 1 a 5, usando a legenda de resposta abaixo (por exemplo, 5 = concordo totalmente).
7	Answer Key.	Modification of words to make the sentence easier to understand.	Legenda de Resposta.
16	I have an empty, sick feeling that my loved one is "gone".	Modification of words to make the sentence easier to understand.	Eu tenho uma sensação de vazio, sensação muito ruim de que meu ente querido "se foi".
20	I miss what we were, had and shared in the past.	Modification of words to make the sentence easier to understand.	Eu sinto falta do que nós éramos, tivemos e compartilhamos no passado.
25	I stay awake most nights worrying about what is going on and how I am going to handle it tomorrow.	Modification of words to make the sentence easier to understand.	Eu fico acordado(a), na maioria das noites, me preocupando com o que está acontecendo e como vou lidar com isso no dia seguinte.
28	Independence is what I lost... I do not have the freedom to go and do what I want.	Inclusion/exclusion/modification of words to make the sentence easier to understand.	Eu perdi minha independência … Eu não tenho liberdade para ir e fazer o que eu quero.
31	MM-CGI-Short version - Personal grief profile.	Modification of words to make the sentence easier to understand.	MM-CGI-Versão Reduzida– Personal grief profile.
40	Deep sadness and Longing (Items B)	Inclusion of words to make the sentence easier to understand.	Sentimentos de profunda tristeza e saudade (Item B).
46	Find your scores using the grid on the right.	Modification of words to make the sentence easier to understand.	**Marque suas pontuações** usando a figura à direita.
57	Low scores (SD below average) can indicate denial or minimize suffering.	Modification of words to make the sentence easier to understand.	Pontuações baixas (um DP abaixo da média) podem indicar negação ou minimização do sofrimento.
60	These are general guides for discussion and support only – further investigation is needed for specific interpretation.	Modification of words to make the sentence easier to understand.	Estas são orientações gerais apenas para discussão e apoio-- mais investigações são necessárias para interpretações específicas.

The 29 elements were modified according to the expert judges' committee suggestions and forwarded to a new evaluation round. The second round detected 2 discordant elements, one corresponding to disagreement in the semantic and idiomatic equivalence and the second to idiomatic disagreement.

Table 2.

Items from the second round of evaluation that obtained a percentage of agreement.

Items	Synthesized translated version	Changes proposed by the second round committee	Final version translated and adapted
2	**Instructions:** This inventory is designed to measure the grieving experience of current Family caregivers of people living with progressive dementia (e.g. Alzheimer's disease).	Word modification to make the sentence easier to understand.	Este inventário foi elaborado para medir a experiência de familiares que são, atualmente, cuidadores de pessoas que vivem com demência progressiva (por exemplo, doença de Alzheimer).
60	These are general guides for discussion and support only – further investigation is needed for specific interpretation.	Exclusion of words.	Para interpretações específicas são necessárias mais investigações.

The suggested modifications were accepted, and a third round of evaluation was carried out and, again, the elements were re-evaluated and adjusted according to the suggestions of the expert judges committee. Elements that did not reach the proposed index were modified according to the committee's suggestions until they reached the necessary equivalence. Three rounds of analysis and modification of the elements were carried out, based on the considerations indicated by the committee of expert judges so that the production of the final version in Portuguese would be possible.

In the fourth round, the objective was to present the final version to the expert judges, and there was no new note or suggestion for modification.

After the fourth round of analysis and by obtaining the equivalences, the equivalence assessment stage was completed. This version was applied to seven family caregivers as the target population (pre-test). Regarding the level of education, 71% of them had higher education, 14% were graduated and 14% had primary education. Kinship indicated that approximately 71% of the participating caregivers were offspring, 14% mother and 14% wife. Table 3 shows the final version translated and adapted for Brazilian culture.

Table 3.

Final version translated and adapted for Brazilian culture.

Legenda de Resposta **1= Discordo Totalmente**/ /2=Discordo // 3 = Concordo um pouco // 4 = Concordo // **5 = Concordo Totalmente**			
1	Eu tive que desistir de muita coisa para ser um(a) cuidador(a).	1 2 3 4 5	A
2	Eu sinto que estou perdendo minha liberdade.	1 2 3 4 5	A
3	Eu não tenho ninguém para conversar.	1 2 3 4 5	C
4	Eu tenho uma sensação de vazio, sensação muito ruim de que meu ente querido "se foi".	1 2 3 4 5	B
5	Eu passo muito tempo me preocupando com as coisas ruins que irão acontecer.	1 2 3 4 5	C
6	A demência é uma perda dupla ...perdi a proximidade com o meu familiar e a conexão com minha família.	1 2 3 4 5	C
7	Meus familiares simplesmente não entendem o que estou passando.	1 2 3 4 5	C
8	Eu sinto falta do que nós éramos, tivemos e compartilhamos no passado.	1 2 3 4 5	B
9	Eu poderia lidar com outras doenças graves melhor do que lido com essa.	1 2 3 4 5	B
10	Não sei por quanto tempo ficarei presa a essa situação	1 2 3 4 5	A
11	É dolorido colocar ela/ele na cama à noite e perceber que ela/ele "se foi".	1 2 3 4 5	B
12	Sinto-me muito triste com o que esta doença fez .	1 2 3 4 5	B
13	Eu fico acordado(a), na maioria das noites, me preocupando com o que está acontecendo e como vou lidar com isso no dia seguinte.	1 2 3 4 5	C
14	Amigos mais próximos de mim não entendem o que estou passando.	1 2 3 4 5	C

15	Eu já perdi outras pessoas próximas, mas as perdas que estou tendo agora são muito mais dolorosas.	1 2 3 4 5	B
16	Eu perdi minha independência … Eu não tenho liberdade para ir e fazer o que eu quero.	1 2 3 4 5	A
17	Eu gostaria de ter uma ou duas horas para mim todos os dias para meus interesses pessoais.	1 2 3 4 5	A
18	Eu estou preso(a) neste papel de cuidador (a) e não há nada que eu possa fazer sobre isso.	1 2 3 4 5	A

Procedimento de auto avaliação: Some os números que você marcou para obter as pontuações nas seguintes subescalas e na pontuação total de luto. Use as letras à direita de cada pontuação para guiá-lo.

Sobrecarga pessoal (Itens A) =

____

(6 itens)

Sentimento de profunda tristeza e saudade (Itens B) =

___________(6 itens)

Preocupação e sentimento de isolamento (Itens C) =

___________(6 itens)

Nível total de luto (Soma A + B + C) =

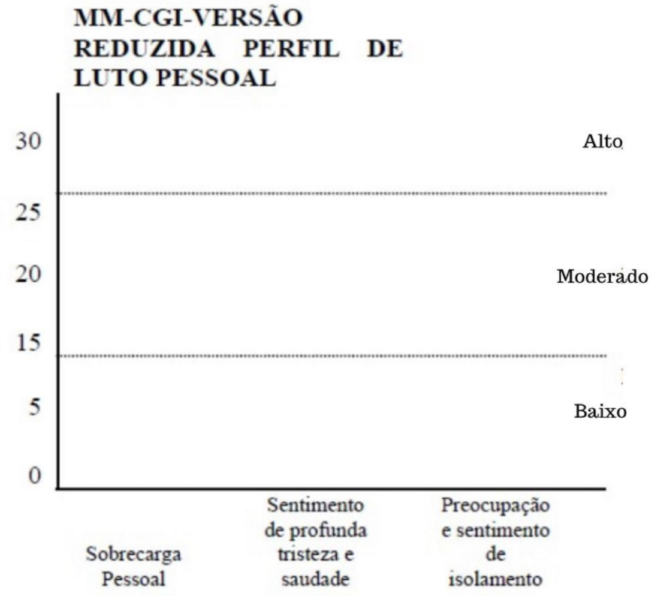
____

(18 itens)

Marque suas pontuações usando a figura à direita. Faça um "X" no número mais próximo de sua pontuação para cada subescala. Ligue os Xs. Este é o seu perfil de luto.

Discuta isso com o profissional que está te acompanhando.

Nota do autor: Esta escala pode ser copiada e usada livremente para fins clínicos ou de apoio. Aqueles que desejam usar a escala para pesquisa devem enviar um e-mail solicitando permissão por meio do contato: meusert@umsl.edu.



Pontuações na área superior são um desvio padrão (DP) maior do que a média, com base nas respostas de outros cuidadores familiares. Pontuações altas podem indicar a necessidade de intervenção ou apoio formal para melhorar o enfrentamento. Pontuações baixas (um DP abaixo da média) podem indicar negação ou minimização do sofrimento. Pontuações baixas também podem indicar adaptação positiva se o indivíduo não estiver mostrando outros sinais de luto não reconhecido ou distúrbio psicológico. Pontuações médias no centro indicam reações comuns. Estas são orientações gerais apenas para discussão e apoio - mais investigações são necessárias para interpretações específicas.

The example in Table 4 shows, at the end of the questions proposed by the inventory, examples of domains A, B and C that will be summed at the end and will indicate the total level of grief. Such results can be presented and visualized in a graph in the inventory itself for better understanding.

Table 4.
Examples of items adapted to Brazilian culture present in the inventory with their respective classifications.

	Questions	**Score**	**Items**
1	I had to give up many things to become a caregiver.	1 2 3 4 5	A
4	I have felt a sensation of emptiness, a very unpleasant sensation that my loved one "left".	1 2 3 4 5	B
3	I have nobody to talk to.	1 2 3 4 5	C

The English and culturally adapted versions of the MM-CGI-SF in Portuguese are shown in Tables 3 and 5.

Table 5.

Culturally adapted answer key.

ANSWER KEY **1 = Strongly Disagree** // 2 = Disagree // 3 = Somewhat Agree // 4 = Agree // **5 = Strongly Agree**			
1	I've had to give up a great deal to be a caregiver.	1 2 3 4 5	A
2	I feel I am losing my freedom.	1 2 3 4 5	A
3	I have nobody to communicate with.	1 2 3 4 5	C
4	I have this empty, sick feeling knowing that my loved one is "gone".	1 2 3 4 5	B
5	I spend a lot of time worrying about the bad things to come.	1 2 3 4 5	C
6	Dementia is like a double loss…I've lost the closeness with my loved one and connectedness with my family.	1 2 3 4 5	C

7	My friends simply don’t understand what I’m going through.	1 2 3 4 5	C
8	I long for what was, what we had and shared in the past.	1 2 3 4 5	B
9	I could deal with other serious disabilities better than with this.	1 2 3 4 5	B
10	I will be tied up with this for who knows how long.	1 2 3 4 5	A
11	It hurts to put her/him to bed at night and realize that she/he is “gone”	1 2 3 4 5	B
12	I feel very sad about what this disease has done.	1 2 3 4 5	B
13	I lay awake most nights worrying about what’s happening and how I’ll manage tomorrow.	1 2 3 4 5	C
14	The people closest to me do not understand what I’m going through.	1 2 3 4 5	C
15	I’ve lost other people close to me, but the losses I’m experiencing now are much more troubling.	1 2 3 4 5	B
16	Independence is what I’ve lost…I don’t have the freedom to go and do what I want.	1 2 3 4 5	A
17	I wish I had an hour or two to myself each day to pursue personal interests.	1 2 3 4 5	A
18	I’m stuck in this caregiving world and there’s nothing I can do about it.	1 2 3 4 5	A

Self-Scoring Procedure: Add the numbers you circled to derive the following sub-scale and total grief scores. Use the letters to the right of each score to guide you.

Personal Sacrifice Burden *(A Items)* = __________ (6 Items, M = 20.2, SD = 5.3, Alpha = .83, n = 292)

Heartfelt Sadness & Longing *(B Items)* = __________ (6 Items, M = 20.2, SD = 5.0, Alpha = .80, n = 292)

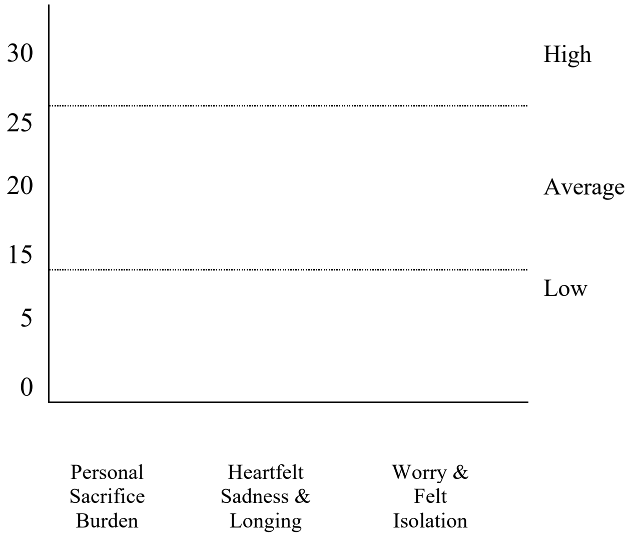
Worry & Felt Isolation *(C Items)* = __________ (6 Items, M = 16.6, SD = 5.2, Alpha = .80, n = 292)

Total Grief Level (Sum A + B + C) =__________ (18 Items, M = 57, SD = 12.9, Alpha = .90, n = 292)

Plot your scores using the grid to the right. Make an “**X**” nearest to your numeric score for each sub-scale heading. Connect the X’s. This is your grief profile. Discuss this with your support group leader or counselor.

Author Note: This scale may be copied and freely used for clinical or supportive purposes. Those wishing to use the scale for research are asked to e-mail for permission: **meusert@umsl.edu** (8/09).

MM-CGI-SF Personal Grief Profile



What do these scores mean?

Scores in the top area are one standard deviation (SD) higher than average based on responses of other family caregivers (n = 292). High scores may indicate a need for formal intervention or support assistance to enhance coping. Low scores (one SD below the mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaptation if the individual is not showing other signs of suppressed grief or psychological disturbance. Average scores in the center indicate common reactions. These are general guides for discussion and support only— more research is needed on specific interpretation issues.

Pilot study

The pilot study aimed to test the application of the MM-CGI-SF. 86 family caregivers of people with dementia, living in the city of Santos, São Paulo, participated in the research. Among them, the degree of kinship with the highest percentage was children (62%), followed by spouses (15%). The age ranged from 31 to 59 years, with 67% of family caregivers in this age group. The schooling of 77.9% of caregivers was over 11 years old. Data from this study are in agreement with the validation of the MM-CGI-SF (2005) in the profiles of participating caregivers, in which most caregivers were also children (51.7%), followed by spouses (42.4%). The schooling mostly found within them was above high school, which corresponds to schooling above 11 years. As in the original study by Marwit and Meuser (2002), in which the caregivers were predominantly female (76.4%), in this sample the female gender also prevailed (74%).

The consistency between the items of the MM-CGI-SF scale was calculated using Cronbach's alpha. The objective was to verify if, in fact, the items of the instrument had correlations with each other (since they measure the same construct). The greater the homogeneity of the content referring to the items, the greater the internal consistency of the instrument.

The analysis of the internal consistency of the MM-CGI-SF scale showed satisfactory correlations between the items. The α values obtained in this study showed a high reliability scale. While in the validation of the original instrument, performed by Marwit and Meuser (2002), Cronbach's alpha coefficients were 0.85, 0.76 and 0.82, respectively, for domains A, B and C, our results indicated alpha coefficients 0.84; 0.81; 0.76, which is also considered a highly reliable scale. Finally, after the last step, the process of translation and cross-cultural adaptation of the elements and items of the MM-CGI-SF was concluded.

Discussion

The present work allowed for the cross-cultural adaptation of the Marwit-Meuser Caregiver Grief Inventory-Short Form to Brazilian culture, which is now called the Marwit-Meuser Caregiver Grief Inventory MMCGI/Short Form. The adopted procedures served to guarantee the semantic, idiomatic, conceptual and cultural equivalences, as well as the face of the instrument and the technical terms of access to the professional of the Brazilian version in relation to the original instrument, according to the methodological recommendations proposed by Borsa (2012). Studies of cross-cultural adaptation of instruments have indicated the importance of the equivalence assessment process so that there are no distortions or discrepancies in language, concepts and cultural aspects between the original versions and those produced in the target language (Fares et al., 2023).The analysis phase of the versions of the Marwit-Meuser Caregiver Grief Inventory/Short Form, by the expert judges committee, made it possible to correct inaccuracies in the translations and adjust the wording of the items to the Brazilian cultural context. Also, the suggestions of caregivers, in the assessment phase with the target population, collaborated to obtain the instrument adapted to the Brazilian reality. During this phase of the process, difficulties of the seven family caregivers in understanding the self-analysis proposed by the instrument were recorded, which requires the sum of the questions in each domain to compose the graph referring to anticipatory grief. The difficulty in self-assessment can be a cultural issue, as it is usually not the target audience that carries out this analysis in Brazilian culture, but the health professionals themselves.

Also at this stage, four of the participants expressed doubts on different issues arising from the difficulty in understanding the question, requiring the help of the researcher. The inventory questions that raised doubts were: “I don't have anyone to talk to”; “I don't know how long I will be stuck in this situation”; “I stay awake most nights worrying about what's going on and how I'm going to deal with it the next day”; "I would like to have an hour or two to myself every day for my personal interests". Each question corresponded to a different participant caregiver, that is, there were no doubts on the same question addressed. As these doubts were made to clarify the question, the professional explained the objective of the question, which helped in understanding and did not generate the need to modify the inventory.

In the pilot study, the analysis of the internal consistency of the MM-CGI-SF scale showed satisfactory correlations between the items, indicating that they are part of the same conceptual dimension. The cross-cultural adaptation comprises several phases, which makes it complex and requires a rigorous task to produce a Portuguese version equivalent to the original instrument that considers relevant adaptations for the culture in which it is being produced. This process gives content validity to the instrument produced for Brazilian culture, renamed the Inventário de Luto de Marwit-Meuser /Versão Reduzida.

In addition to the Portuguese version, the Chinese, Turkish and English versions also maintain the structure of the original instrument with 18 questions, with the distribution of the items in a five-point Likert scale, ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). The 18 questions addressed in the inventory are divided into subscales classified by domains (A, B and C). Each of the three domains has six questions. Domain A assesses personal overload, B the feeling of deep sadness and longing and C the concern and feeling of isolation. At the end of the questions proposed by the inventory, the sum of the scores in each domain A (6 items), B (6 items) and C (6 items) indicates the total level of grief (A+B+C) which may vary from 18 to 90 points.

Such result can be presented and visualized in a proposed graph for better understanding. The sum and location in the graph in the Portuguese version can be completed by the professional who is carrying out the assessment, as family caregivers had difficulty calculating the score and locating the level of grief on the graph.

The data obtained in the assessment with the target population confirmed the need to apply to a larger sample to produce data with evidence of internal and external validity, as well as to discuss with the authors of the original version the possibility of the self-assessment turning into an assessment performed by health professionals.

Final Considerations

The translation and cross-cultural adaptation of the Marwit-Meuser Caregiver's Grief Inventory/Short Form was carried out for the Brazilian context. The assessments of semantic, idiomatic, cultural and conceptual equivalence, performed by the members of the Expert Committee, had a positive outcome. The validation study of this instrument is in progress.

This instrument allows the assessment of the anticipatory grief of family caregivers of people with dementia, enables interventions proposed by various health professionals, assists in research on losses related to grief experienced by family caregivers, and can provide early referrals to specialized clinicians and more effective targeted interventions, such as; support groups for caregivers, therapeutic and psychotherapeutic groups.

There are still challenges to be faced so that the translated instrument can be consolidated as a reliable measure for assessing grief in caregivers of individuals with dementia. Therefore, it is essential to plan future research that includes representative samples, in order to allow the comparison of the factorial structure of the Marwit-Meuser Caregiver Grief Inventory/Short Version with the theoretical principles that supported its development.

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