

ORIGINAL ARTICLE

Validation of the caregiver version of the Comprehensive Score for Financial Toxicity instrument in Brazilian Portuguese*

HIGHLIGHTS

1. Providing an instrument for research on financial toxicity.
2. COST caregivers instrument translated and validated into Brazilian Portuguese.
3. Good internal consistency; Cronbach's alpha coefficient of 0.86.
4. Contributes to the development of studies focused on financial toxicity.

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ABSTRACT

Objective: To translate, adapt, and evaluate the psychometric properties of the caregiver version of the *Comprehensive Score for Financial Toxicity* for the Brazilian context. **Method:** A methodological study conducted between February and November 2025 in a medium-sized municipality in northwestern Paraná, Brazil. The process consisted of two sequential stages: translation and cross-cultural adaptation, following the methodological framework of the *Functional Assessment of Chronic Illness Therapy* group; and psychometric evaluation of the Brazilian version, administered to informal caregivers. **Results:** The scale showed good internal consistency, with a Cronbach's alpha of 0.868, indicating high homogeneity among the items, and the total omega was 0.790, a value considered adequate for unidimensional instruments. **Conclusion:** The version of the *Comprehensive Score for Financial Toxicity* questionnaire for informal caregivers demonstrated confirmatory factor analysis, revealing a unifactorial structure with 12 items and presenting adequate fit indices, thereby supporting the proposed model.

DESCRIPTORS: Financial Stress; Caregivers; Translating; Validation Study; Home Nursing.

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INTRODUCTION

Financial toxicity is defined as a set of financially burdensome adverse health-related effects—such as diagnostic tests, treatments, and medications, among others—that impact individuals' lives and economic stability, directly affecting their physical health, emotional well-being, and quality of life¹.

The concept first emerged in the field of oncology in response to the need to assess the impact of costs associated with medications, treatments, hospitalizations, and travel to specialized care facilities, which affect treatment adherence and continuity of care².

In the United States of America (USA), the first studies aimed at understanding this financial burden associated with cancer treatment were conducted. In this context, the *Comprehensive Score for Financial Toxicity* (COST), was developed by the U.S. group *Functional Assessment of Chronic Illness Therapy* (FACIT) with the aim of measuring, in a standardized manner, the financial toxicity experienced by patients³. In Brazil, the instrument was translated and adapted into Portuguese in 2020, preserving the original structure, number of items, and scoring system⁴.

However, the phenomenon of financial toxicity is not limited to people with cancer; it is currently being studied in other costly diseases⁵⁻⁶ and also among family members who take on the role of caregivers. These caregivers assume, on an unpaid basis, the responsibility for the daily and ongoing care of dependent individuals. In addition to the physical and emotional demands inherent in caregiving, they often bear various direct and indirect costs related to maintaining the health of the caregiver-dependent dyad, such as medical appointments, tests, procedures, medications, home modifications, orthotics, and prosthetics⁷⁻⁸. These costs are added to the family's existing expenses and can severely compromise the household's income and financial stability.

Despite the relevance of the topic, there are still few national and international studies investigating financial toxicity from the perspective of informal caregivers, a gap that limits a comprehensive understanding of this phenomenon in different caregiving contexts. To address this need, the COST Caregivers Questionnaire was developed, a 12-item instrument specifically designed to assess financial toxicity among informal caregivers⁹. Although it has already been validated internationally, it is currently available only in English, making its translation, cross-cultural adaptation, and psychometric evaluation necessary for use in the Brazilian context.

In this context, the present study aimed to translate, adapt, and evaluate the psychometric properties of the *Comprehensive Score for Financial Toxicity* (COST) Caregivers version for the Brazilian culture.

METHOD

This is a methodological study conducted between February and November 2025 in a medium-sized municipality in northwestern Paraná, Brazil. The process consisted of two sequential stages: (1) translation and cross-cultural adaptation of the instrument; (2) psychometric evaluation of the Brazilian version.

For Stage 1, we adopted an adapted version of the FACIT¹⁰ methodological framework, following four main phases: 1) Direct translation (*forward translation*): performed independently by two bilingual translators (T1 and T2), who produced separate versions of the instrument; 2) Reconciliation: a third translator compared the two versions and produced a synthesized version, resolving linguistic and conceptual discrepancies; 3) Back-translation: a fourth translator, a native English speaker fluent in

Portuguese, translated the reconciled version back into English; and 4) Review by the instrument developers: all versions (originals, translations, and back-translation) were sent to the instrument's authors to verify conceptual equivalence. It should be noted that no pretest was conducted in this study and that the instrument developers monitored all phases of the process. All translators were professionals and were found through a translation services website called Catálogo de tradutores (Translator catalogue). All were paid for their translation work.

In Stage 2, the Brazilian version of the COST Caregivers questionnaire was administered to a sample of 200 informal caregivers of patients hospitalized in the medical-surgical and emergency care units of the Maringá Regional University Hospital (HUM) in Paraná. The inclusion criteria for caregivers in this stage were: being an informal caregiver; being aged ≥ 18 years; and caring for a family member hospitalized in the aforementioned departments. In addition, to recruit informal caregivers, the Fugulin scale¹¹ was administered to the patient to confirm the need for care. Those with intermediate dependency (≥ 18) were also included. Exclusion criteria included: caregivers with professional training to perform caregiving activities, since, according to the Ministry of Health¹², a caregiver is still considered informal even if they receive compensation paid by the rest of the family for providing care; however, they are considered a formal caregiver if they have specific training for the role.

The participants answered three instruments, in printed version, namely: sociodemographic questionnaire, containing information on age, gender, education, income, marital status and profession; clinical questionnaire, with data related to the care provided (time as a caregiver, family members' conditions, degree of proximity, support network, financial aid, work activity, comorbidities, medications and health insurance); in addition to information related to the family member cared for, such as age, recent hospitalizations, time of dependence, continuous medications, use of enteral diets and medical devices at home, in addition to medical follow-up in places that require locomotion, degree of dependence and the COST Caregivers.

The COST Caregivers consists of 12 items addressing the following issues: I know I have sufficient financial resources, in savings, retirement funds, or assets, to cover the costs of my loved one's treatment; the amounts I've had to pay out of pocket to cover my loved one's medical expenses have exceeded what I expected to pay; I am concerned about the financial problems I will face in the future as a result of my loved one's illness or treatment; I feel I have no choice regarding how much I spend on my loved one's healthcare; I feel frustrated that I cannot work or contribute as much as I used to; I am satisfied with my current financial situation; I am able to manage my monthly expenses; I feel that I am experiencing financial difficulties; I am concerned about keeping my job and my income, including the paid work I do at home; my loved one's cancer or treatment has reduced my satisfaction with my current financial situation; I feel that I am in control of my financial situation; my loved one's illness has caused financial difficulties for me and my family. The last item was considered a summary of all the questions.

Responses are rated on a five-point *Likert* scale, ranging from zero (not at all) to four (very much). Scores range from zero to 44 points and are classified into four levels, as suggested by the Japanese group¹³. Level 0: score above 26 (no impact); Level 1 (mild impact): score between 14 and 25; Level 2 (moderate impact): score between 1 and 13; Level 3 (high impact): score of zero.

It should be noted that, in the data analysis, items 2, 3, 4, 5, 8, 9, 10, and 12 were reversed in order to maintain the consistency of the instrument's scoring—the higher the score, the lower the financial toxicity. Therefore, when calculating the final score, the reversed items assign a score of four to the worst response and a score of zero to the best response.

The data were entered independently by two members of the research team, using double data entry in *Microsoft Excel* to verify consistency. Statistical analyses were conducted using *RStudio* software, version 2023.12.0.36; a significance level of 5% was adopted.

To evaluate whether the original unifactorial model provides a good fit to the data, a Confirmatory Factor Analysis (CFA) was performed using the WLSMV estimator. Information on model discrepancies, derived from the modification indices, was used for possible *post hoc* respecifications, with values greater than 10 serving as the criterion.

The model fit was assessed using the χ^2 statistic, CFI (*Comparative Fit Index*), TLI (*Tucker-Lewis Index*), RMSEA (*Root Mean Square Error of Approximation*), and SRMR (*Standardized Root Mean Square Residual*). The χ^2 test assesses the discrepancy between the observed correlation matrix and that reproduced by the model; however, because it is sensitive to sample size, its interpretation must be supplemented by the other indices. The CFI and TLI values, which compare the proposed model with a null model, range from zero to one, with values ≥ 0.90 already indicating a good fit¹⁴. The RMSEA quantifies the population approximation error, with values ≤ 0.06 considered acceptable¹⁵, while values ≥ 0.10 reflect poor fit¹⁶. The SRMR, in turn, measures the average discrepancy between observed and estimated correlations; values < 0.08 suggest a good fit¹⁵.

In addition to the global indices, the polychoric residuals were examined, which indicate the degree of underestimation or overestimation of the relationships between pairs of variables. Residuals between -0.10 and 0.10 are considered acceptable, suggesting that the model adequately represents the observed correlations.

Following confirmatory factor analysis, the data were initially described using absolute frequencies and percentages (qualitative variables) and measures such as mean, standard deviation, minimum, median, and maximum (quantitative variables).

Floor/ceiling effects were analyzed by the percentage of participants who achieved the lowest or highest possible score, respectively. The presence of these effects can be considered relevant if more than 15% of the participants reach one or another extreme score¹⁷.

The internal consistency of the scale was assessed based on the original nature of the 12 items (0–4). The mean of the polychoric inter-item correlations was used as a general measure of consistency among the items. Next, the corrected item-total correlations—also derived from the polychoric matrix—were calculated; these indicate each item's individual contribution to the total score, accounting for its own influence on the total calculation. Values < 0.30 were considered indicative of a potentially weak item¹⁸. Overall internal consistency was estimated using *Cronbach's* ordinal alpha¹⁹ and McDonald's total omega coefficient (ω), which incorporates the instrument's factor structure²⁰.

Each item in the instrument was referred to as Q (item) followed by its numerical order (e.g., Q1). When it was necessary to reverse the scoring of an item, the term *inv* was used (e.g., Q2inv).

The project was approved by the Human Subjects Research Ethics Committee under approval number 7,489,760 and was conducted in accordance with Resolution No. 466/2012 and Resolution No. 510/201, which regulate research involving human subjects. In addition, the study was authorized by the FACIT group.

RESULTS

Stage 1

Translations 1 and 2 were translated without major disagreements between the items; However, the same did not occur between the answers. There was a discrepancy between T1's first answer option, which translated as "Not at all," and T2's, "Not at all." In the reconciliation, T3 chose to keep "By no means". After back-translation, the instrument was sent to the developers, who requested that this answer be adjusted to "Not at all" in order to maintain similarity with the original questionnaire. The words "my loved one's" were also inserted in items 1, 2, 3, 4 and 12 to accommodate the instrument to the respondent, in this case the caregiver. Once these adjustments were made, the translation and cross-cultural adaptation stage was closed.

Stage 2

The psychometric assessment sample was composed of 200 informal caregivers, with a median age of 55 years, predominantly female (81.5%), married (65.5%) and with complete high school education (35.5%). The majority (54%) were children of the care recipient and had been caring for the family member for less than a year (46%). A high frequency of comorbidities (62.5%) and continuous use of medications (59%) were identified. Regarding socioeconomic conditions, 90% reported not receiving government financial aid, 63% did not have an employment relationship, 78% lived in their own home and 53.5% lived with the family member under their care (Table 1).

Table 1. Sample characterization (n=200). Maringá, PR, Brazil, 2025

(continue)

Variable	N=200
Age	
Medium (min.- max.)	55.00 (20.00; 76.00)
Sex	
Female	163 (81.5%)
Male	37 (18.5%)
Marital status	
Married	131 (65.5%)
Single	38 (19.0%)
Education	
Incomplete fundamental	61 (30.5%)
Completed Medium/Technical	71 (35.5%)
Family relationship	
Son/daughter	108 (54.0%)
Spouses/Partners	34 (17.0%)
Time as a caregiver	
< 1 year	92 (46.0%)
1 to 4 years	42 (21.0%)

Table 1. Sample characterization (n=200). Maringá, PR, Brazil, 2025

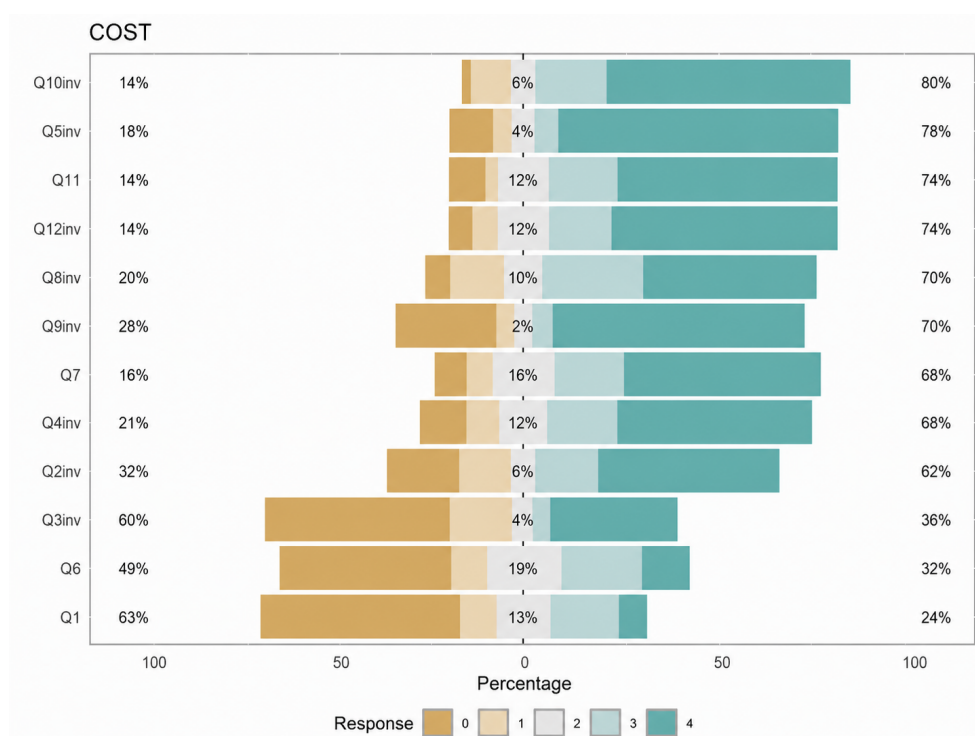
(conclusion)

Variable	N=200
Government financial aid	
No	180 (90.0%)
Yes	20 (10.0%)
Employment relationship	
No	126 (63.0%)
Yes	74 (37.0%)
Lives in her own home	
No	44 (22.0%)
Yes	156 (78.0%)
Lives with the family member	
No	93 (46.5%)
Yes	107 (53.5%)

Note: The total number of 200 participants was not included in the variables "Marital status", "Education", "Family Relationships" and "Time as a caregiver", as only the most scored answers within the sample were presented.

Source: The authors (2025).

The descriptive analysis of the scale reveals heterogeneity among the items: some have responses that are heavily concentrated in positive values (high scores of 3 to 4), while others are concentrated in negative values (low scores of 0 to 1). The following figure shows the distribution of responses for each item on the questionnaire, particularly at the extremes (responses 4 and 0) (Figure 1).

**Figure 1.** Descriptive analysis of the scale. Maringá, PR, Brazil, 2025

Legend: Q=question; Qinv=inverted questions at the time of statistical analysis.

Source: The authors (2025).

In the confirmatory factor analysis (CFA), a unifactorial structure with 12 items was considered, showing adequate fit indices (RMSEA = 0.075; CFI = 0.954; TLI = 0.941; SRMR = 0.076), supporting the proposed model. Overall, the items performed well (Table 2).

Table 2. Description of CFA values with adjusted indices. Maringá, PR, Brazil, 2025

The index	Model	Respecified Model*
RMSEA	0.104 (CI90%: 0.086-0.121)	0.075 (90% CI: 0.055-0.094)
CFI	0.907	0.954
TLI	0.887	0.941
Chi-square	169.473 (54)	109.438 (52)
SRMR	0.098	0.076

Note: Considering correlation between errors. RMSEA - ; CI - ; CFI - ; TLI - ; SRMR - .

Source: The authors (2025).

The RMSEA indicates how well the model fits the actual data. In the initial model, the RMSEA was 0.104, indicating insufficient fit. After allowing for correlation between the errors of two items, as suggested by the modification indices, the RMSEA dropped to 0.075, indicating an adequate fit.

The CFI assesses whether the model fits better than a null model (with no relationships between variables). In the initial model, the CFI was adequate (0.907) and improved further after respecification (0.954). The TLI also compares the model to a null model but penalizes for complexity. The TLI increased from 0.887 to 0.941, demonstrating a clear improvement in fit after accounting for correlated errors.

The chi-square value decreased significantly in the respecified model, along with a reduction in the degrees of freedom, indicating that the adjusted model better describes the data.

The SRMR reflects the average discrepancy between the observed and reproduced correlations. The initial model had an SRMR of 0.098 (above the ideal), but after respecification, the index fell to 0.076, indicating an adequate fit.

Thus, a correlation was observed between items Q7 and Q11 (modification index 37.891), such that a positive response to one of the items would imply a negative response to the next. Items Q5inv and Q9 (modification index 13.926) were found to be logically related, since a negative response to one of them would logically imply a negative response to the next.

Items Q4inv and Q9inv consistently showed lower factor loadings and less explained variance. Although this does not compromise the scale's use, these items represent opportunities for improvement in future versions.

The scale showed good internal consistency, with a *Cronbach's alpha* of 0.868, indicating high homogeneity among the items, and the total omega was 0.790, a value considered adequate for unidimensional instruments²¹. The mean polychoristic correlation among the items was 0.355, confirming that the items are consistently related without being redundant.

Overall, most items exhibited satisfactory factor loadings (>0.40). However, items Q4inv and Q9inv showed lower loadings (0.329 and 0.391), suggesting that their relationship with the construct may be weaker (Table 3).

Table 3. Standardized estimate of factor loadings. Maringá, PR, Brazil, 2025

Factor	Item	Factor loadings	Standard Error	P-value
F1	Q1	0.635	0.059	0.000
F1	Q2inv	0.411	0.069	0.000
F1	Q3inv	0.560	0.062	0.000
F1	Q4inv	0.329	0.080	0.000
F1	Q5inv	0.556	0.074	0.000
F1	Q6	0.755	0.049	0.000
F1	Q7	0.679	0.056	0.000
F1	Q8inv	0.762	0.042	0.000
F1	Q9inv	0.391	0.081	0.000
F1	Q10inv	0.739	0.054	0.000
F1	Q11	0.561	0.065	0.000
F1	Q12inv	0.789	0.046	0.000

Legend: Q - Question; Qinv - Question with inverted punctuation.

Source: The authors (2025).

It should be noted that items 2, 3, 4, 5, 8, 9, 10, and 12 were reversed in order to standardize the individual score for each item with the instrument's final score. The stratification follows the principle that the higher the individual's final score, the lower the impact of financial toxicity. Therefore, at the end of the instrument administration, during scoring, the scores for the aforementioned items must be reversed, as follows: if the individual's response to the question is four, zero will be added to the final overall score; three will be added one; and a response of two remains unchanged, as it is considered the neutral score on the scale.

DISCUSSION

This study cross-culturally adapted and analyzed the psychometric properties of the COST Caregivers—a version designed to assess financial toxicity in informal caregivers. The relevance of this topic is recognized worldwide and highlights a reality that has been largely unexplored in the Brazilian literature: the financial distress of informal caregivers.

Families caring for dependent older adults or seriously ill patients often require costly treatments and/or long-term care, necessitating a reorganization of the family structure⁷⁻⁸. This reorganization goes beyond physical dependence and extends to even more complex dimensions, such as financial considerations.

The challenge of managing patient care alongside the expenses associated with that care often remains hidden and largely overlooked by public organizations and healthcare professionals, which can push caregivers to their physical and mental limits. This intense strain, combined with daily fatigue, contributes to the development of physical illnesses related to neglect of one's own health; as for psychological distress, it stems from a lack of a support network and social isolation resulting from the number of hours devoted solely to caregiving²².

When considered in relation to the working-age population, the financial burden can be even more severe. Becoming a caregiver for a dependent person can entail greater financial burdens linked to family reorganization, due to the need to leave one's job or reduce working hours, which impacts family income²³. A similar pattern can be observed in this sample, in which caregivers had a median age of 55 years: 63% were not engaged in paid work, and 90% did not receive any government assistance or benefits.

Furthermore, older caregivers often rely solely on a retirement pension to cover the entire family's expenses. One must also consider the fact that the dependent person may once have been the family's sole or primary source of income, but, following the onset of the illness, can no longer contribute financially to the family's livelihood²⁴.

Informal caregivers continue to be neglected by government agencies, public policies, and even health care services, being viewed solely in terms of their obligations as caregivers, without being offered resources or strategies to effectively manage all the burdens (physical, mental, and financial) associated with caregiving. It is essential that public policies address the various demands of caregiving, and that health professionals take caregivers' needs into account when planning care, in order to address their specific circumstances and promote the well-being of the family unit²⁵.

In this regard, the COST version, translated and validated using robust and reliable methods, serves as a strategic tool that can be used by healthcare professionals and managers, as it provides insight into the financial aspects of care and their implications for the health-disease process. The instrument proves to be particularly important during transitions in care, when family dynamics and roles are undergoing change, representing a critical period for the family⁷. Based on this analysis, it is possible to identify the concerns and challenges faced and to activate the various resources within the network to support the caregiver.

The instrument was translated following all the steps proposed by the FACIT group and was subsequently validated by a sample of 200 informal caregivers, confirming its reliability. Items Q4inv and Q9inv had factor loadings <0.40 ; however, they did not deviate significantly from the recommended values, thus yielding a p -value <0.001 . It should be noted that, during data collection, caregivers had some difficulty understanding these questions, especially item Q4inv. However, both items are important for the final design of the instrument, as they address the financial assistance received and concerns about work.

Cronbach's *alpha* was considered a great result, 0.868. This result is similar to that found in the validation of the COST questionnaire for patients undergoing cancer treatment into Portuguese, in addition to the Italian and North American validations²⁶⁻²⁷, which also presented similar results.

As a limitation of the study, the floor and ceiling effect was observed, which consists of the percentage of participants, based on the overall score, who obtained scores very close to the extremities.

Analysis of the distribution of total COST scores revealed no floor effect, as no participant scored near the minimum possible score, indicating that the scale has good sensitivity for detecting lower levels of financial toxicity. In contrast, a ceiling effect of 11.5% was observed (using 15% as the cutoff point), suggesting that a considerable proportion of participants achieved very high scores (≥ 43.2). This may indicate a limitation of the scale in adequately distinguishing higher scores, which reflect lower financial toxicity in the evaluated sample.

Despite these limitations, it is necessary to consider the specific characteristics of the sample used to validate the instrument, which may not reflect the reality of the Brazilian population. Therefore, it should be understood that such ceiling effects may be

linked to the evaluated population and not to the instrument itself. This is compounded by the fact that caregivers were contacted while the patient was still hospitalized and that 46% had been serving as caregivers for less than a year, which may, in part, affect the actual costs of home care—costs that these individuals likely had not yet incurred.

It should be noted that the sample came from a public hospital, which provides care exclusively through the Unified Health System (SUS); the municipality's healthcare network, in conjunction with nongovernmental partnerships, meets a significant portion of care-related needs free of charge. However, during data collection, it was noted that the main concerns related to the costs of care were prolonged hospital stays, which resulted in the need to take time off from work.

The version of the questionnaire designed for cancer patients⁴ indicates that the instrument can be self-administered—that is, completed by the patient with the assistance of a researcher or healthcare professional. However, during data collection, it became apparent that the instrument needed to be administered by a healthcare professional.

In addition, some of the information might differ if the caregiver were interviewed at home, since they would already be experiencing the caregiving process and its associated burdens and might feel more comfortable answering sensitive questions outside of a hospital setting

CONCLUSION

The COST version for informal caregivers underwent confirmatory factor analysis, which revealed a unifactorial structure with 12 items. It showed adequate fit indices (RMSEA = 0.075; CFI = 0.954; TLI = 0.941; SRMR = 0.076), supporting the proposed model. Overall, the items performed well. However, items four and nine consistently had the lowest factor loadings and the least explained variance. Although this does not compromise the scale's use, these items represent opportunities for improvement in future versions.

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