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#### ORIGINAL ARTICLE

# Psychometric properties of Persian version of the Caregiver Burden Scale in Iranian caregivers of patients with spinal cord injury

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#### **ABSTRACT**

Purpose: To investigate the psychometric properties of the Persian version of Caregiver Burden Scale (CBS) in caregivers of patients with spinal cord injury.

Methods: This is a cross-sectional study. After a forward-backward translation, the CBS was administered to 110 caregivers of patients with spinal cord injury (men = 60, women = 50). Factor structure was evaluated by confirmatory factor analysis. The Internal consistency and test-retest reliability of the CBS were examined using Cronbach's  $\alpha$  and the intraclass correlation coefficient, respectively. Construct validity was assessed by examining the relationship among CBS and the World Health Organization Quality of Life, and the Beck Depression Inventory.

Results: The results of confirmatory factor analysis provided support for a five-factor model of CBS. All subscales of CBS revealed acceptable internal consistency (0.698-0.755), except for environment subscale (0.559). The CBS showed adequate test-retest reliability for its subscales (0.745-0.900). All subscales of CBS significantly correlated with both Beck Depression Inventory and World Health Organization Quality of Life, confirming construct validity.

Conclusions: The Persian version of the CBS is a valid and reliable measure for assessing burden of care in caregivers of patients with spinal cord injury.

#### ➤ IMPLICATIONS FOR REHABILITATION

- Spinal cord injury leads to depression, high levels of stress and diminished quality of life due to the high physical, emotional, and social burdens in caregivers.
- Persian version of the Caregiver Burden Scale is a valid and reliable tool for assessing burden in Iranian caregivers of patients with spinal cord injury.

#### **ARTICLE HISTORY**

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#### **KEYWORDS**

Caregiver Burden Scale; caregiver; spinal cord injury; psychometric properties; Persian

#### Introduction

Spinal cord injury (SCI) is one of the most disturbing physical damages which make biopsychosocial consequences that affect different life domains depending on the neurological level of injury and often leads to a dependent lifestyle for performing daily living activities and social participation.[1-3] Typically, people responsible for caring and supporting patients with SCI are their families and relatives.[1,4] A caregiver is a person who provides support and assistance, formal or informal, with various activities for people with disabilities and long-term conditions, or elders. [1,5] Caregivers provide different types of support such as emotional, physical, financial, and hands-on help with different activities of daily living.[1,5,6] Despite lack of any formal or informal training, they become responsible for providing professional supports such as taking medications, rehabilitation, or medical emergencies.[1,5,7] Thus, caregiver is intricately tied to the wellbeing of the individual with SCI which can lead to depression, high levels of stress,[7,8,9] and diminished quality of life due to high levels of physical, emotional, and social burdens in many caregivers.[4,10,11] However, there is limited evidence about the quality of life and its effective factors in the caregivers of patients with SCI, which seems to result from lack of an appropriate assessment tool.[1] It is crucial to identify burnout risk factors such as burden and depression via valid assessment tools to prevent them.

Caregiver burden is the emotional, physical, and financial demands in addition to responsibilities that are placed on family members, friends, or others outside the health care system because of an illness in a dear one.[5,10] Various tools such as Zarit Burden Interview and Caregiver Burden Inventory are designed to assess caregiver burden in chronic diseases e.g., Alzheimer, stroke, Parkinson.[12-16] Upon review, the Caregiver Burden Scale (CBS) appears to be the most effective tool to assess the burden imposed on caregivers of chronic patients, especially people with SCI.[4-6,10,17] Graca et al (2013) suggested that CBS is an appropriate tool for evaluating the quality of life and burden levels in caregivers of patients with SCI is more than Short Form (36) Health Survey.[4] The CBS is a modified scale of the original scale developed by Oremark [18], used to assess the caregivers of chronic patients. The original version included 20 items; however, two further items were added using exploratory factor analysis of 150 caregivers by Elmstal et al, and as a result, a scale including 22 items in five categories was developed.[19] This scale consisted

of five domains: general strain (8 items), isolation (3 items), disappointment (5 items), emotional involvement (3 items), and environment (3 items). CBS has been validated in English and Portuguese languages so far.[19,20]

Considering the lack of a validated instrument to measure the burden imposed on Persian-speaking caregivers of patients with SCI, CBS seems to be an appropriate choice. So, the present study was designed and implemented to translate and culturally adapt the CBS for Persian-speaking caregivers of individuals with SCI, and to test the psychometric properties of this Persian version of CBS as well.

#### Material and methods

The participants in the present cross-cultural translation and psychometric testing study were caregivers of community-dwelling individuals with SCI. Participants were enrolled from Brain and Spinal Injury Repair Research Center of Tehran, Iran from June until October, 2014. The inclusion criteria for caregivers were as follows: family members who spend more than 11 h a day with a patient for at least a year; age between 18-60 years old; native Persian speaker; ability to read and write in Persian; and an education level of grade five or higher. Caregivers with chronic conditions such as diabetes or heart disease or neurologic disorders were excluded.

#### **Procedure**

As the patients were visited by occupational therapists, caregivers who met the mentioned inclusion criteria were asked to participate in the present study. All participants signed the written informed consent and then, in the presence of principal investigator completed the questionnaires CBS, World Health Organization Quality of Life (WHOQOL\_BREF), and Beck depression inventory II

Variable numbers of participants were recruited for each phase of study: 14-caregiver for face validity, 110-caregiver for construct validity, factor analyses and internal consistency reliability, and for test-retest reliability, 54 people of participants in validity phase were chosen randomly after 2 weeks time interval. Also, 14 specialists performed the content validity.

The Ethics Committee of Iran University of Medical Sciences approved the study design.

# **Translation**

Principal investigator obtained the permission for translation and cultural adaptation of the CBS from English to Persian language from the main developer of the scale. The translation process was based on the published guidelines.[21]

For the first stage, two independent professional translators, proficient in native Persian language, produced two separate Persian translations of the CBS. An expert panel consisting of the two mentioned translators, the authors, and three rehabilitation professionals reviewed the original translations and produced a single agreed-upon version of the scale. After producing the final version of the translation, two additional certified bilingual translators, unfamiliar with the scale, translated the Persian scale back into English. The Persian version of the CBS was compared to both the reverse English translation and the original English CBS version. The final reverse translation of the CBS was confirmed by the original CBS developer and thus, the Persian version of the CBS was developed.

#### Face validity

The aim of this phase was to examine the understandability of the pre-final Persian version of CBS. Fourteen participants (eight male, mean age 44 years; six female, mean age 39 years) completed the scale. Each participant answered the scale to determine the clarity, relevancy, and simplicity of the items. The principal investigator encouraged the caregivers to mention and discuss those items that were difficult and ambiguous to understand.

#### **Content validity**

Both qualitative and quantitative methods were used to establish the content validity scores. For the qualitative method, an expert panel consisting of 14 specialists (eight occupational therapists, three nurses, and three physical therapists) evaluated each item based on grammatical and semantic points. Experts had at least five years of experience in clinical practice with SCI patients.

Quantitative content validity was calculated using the content validity ratio (CVR) and content validity index (CVI).[22] To calculate the CVR based on the Lawshe method, the degree of the essentiality of each item was assessed using a 3-point rating scale: (a) essential, (b) useful but not essential, (c) unessential. Values equal to or above 0.4 for each question were considered acceptable. CVI was measured by calculating the mean CVR of items of the scale.

#### **Construct validity**

To test the construct validity, the correlation among the Persian version of BDI II, the WHOQOL-BREF, and the CBS was measured.

We hypothesized that the WHOQOL would negatively correlate with the CBS while the correlation between BDI II and CBS would be positive. In this phase, 110 participants completed the three above-mentioned questionnaires, which were presented in a random order.

#### Instrument

#### Careaiver Burden Scale

CBS is a multidimensional scale assessing the subjective impact of burden of taking care of people with chronic diseases. It includes 22 items and is divided into five domains: general strain (eight items), isolation (three items), disappointment (five items), emotional involvement (three items), and environment (three items). Each item is rated on a scale of 1 to 4 (1 = not at all, 2 = seldom, 3 = sometimes, and 4 = often), with a higher value representing greater perceived burden. The individual score is either calculated separately to determine the domain value, or jointly (the total value of the 22 items) which can be reported as raw total or mean score of items. The overall score is obtained by calculating the arithmetic mean of 22 items, and the score for each domain is obtained through the arithmetic average of the value of each item comprising that domain.[10,19]

#### WHOQOL-BREF

WHOQOL is one of the best known tools for evaluating the quality of life in more than 40 languages.[23] The scale was developed in 1998 and assesses quality of life over four domains: physical health (7 items), psychological health (6items), social relationships (3items), and environmental health (8items). The acceptable reliability and validity of the Persian version of WHOQOL in the Iranian population has been documented. The Cronbach's  $\alpha$  coefficient for Persian version of WHOQOL-BREF and its subscales were within the

acceptable range (Cronbach's  $\alpha > 0.70$ ), except for social relationship ( $\alpha = 0.55$ ).[23] The WHOQOL-BREF is the most acceptable and established instrument to assess quality of life in patients with SCI.[24]

#### BDI-II

This questionnaire consists of 21 items, assessing the severity of depression in adults and adolescents over 13 years of age.[25,26] The questionnaire has four possible answers, 0-3, with higher values representing a higher level of depression.

The Persian version of this questionnaire is documented [26] with a Cronbach's  $\alpha$  coefficient of 0.87.

### Statistical analysis

Content and face validity were assessed by CVR and CVI. Confirmatory factor analysis was used to investigate the factor structure of the CBS. The model was tested using covariance matrix and maximum-likelihood estimation method. To assess model fit, we used the chi-square statistic ( $\chi^2$ ), relative/normed chi-square ( $\chi^2/df$ ), the goodness of fit index (GFI), the comparative fit index (CFI), Tucker-Lewis index (TLI), the root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR). The  $\chi^2$  statistic is the most common method for evaluating goodness of fit, but it is highly sensitive to sample size. An alternative evaluation of the  $\chi^2$  statistic is to examine the relative/normed chi-square  $(\gamma^2/df)$  for the model. A  $\gamma^2/df$  ratio of less than 3 is considered indicative of a good fit between the hypothetical model and the sample data. For other goodness of fit indexes, values indicative of good fit are GFI, CFI, and TLI >0.95, RMSEA <0.06 and SRMR <0.08.[27,28] The internal consistency of the CBS was examined using Cronbach's  $\alpha$ , and the test-retest reliability of the scale was evaluated using intraclass correlation coefficient (ICC). To examine the construct validity of the CBS, Pearson correlation coefficients were calculated among the CBS, BDI, and WHOQOL-BREF.

All data analyses were carried out using SPSS software version 21.0 (SPSS Inc., Chicago, IL), except for the CFA, which was conducted using AMOS version 20.0. All statistical tests were 2-sided and the level of statistical significance was set at 0.05.

#### **Results**

Table 1 shows the demographic characteristics of the participants. 116 caregivers completed the above-mentioned questionnaires, of which nine questionnaires were imperfectly completed. So, the questionnaires were given to three other caregivers to consider the minimum intended samples for the calculation of CBS psychometric properties. In total, 110 caregivers (60 male, 50 female; mean age  $37.61 \pm 12.10$  years; age range 18-60 years) completed these questionnaires. Educational level in participants was as follows: 27.3% in elementary education, 40.9% in high school, and 31.8% had university degrees. Of them, 17.3% were full time and 33.6% were part time employees, and 49.1% were unemployed.

# **Factor analysis**

The confirmatory factor analysis was used to evaluate the goodness of fit of the five-factor model of CBS in 110 participants. The results of confirmatory factor analysis provided support for a five-factor model of CBS ( $\chi^2 = 222.15, df = 188, p = 0.045; \chi^2/$ df = 1.18; GFI = 0.921; CFI = 0.956; TLI = 0.946; RMSEA = 0.041and SRMR = 0.052). All standardized factor loadings showed in

Table 1. Demographic characteristics of caregivers of patients with SCI (n = 110).

	n (%)
Age (years) (Mean ± SD)	37.61 ± 12.10
Gender	
Male	60 (54.5)
Female	50 (45.5)
Education level	
Elementary	30 (27.3)
High school	45 (40.9)
University degree	35 (31.8)
Occupation	
Unemployed	54 (49.1)
Part time	37 (33.6)
Full time	19 (17.3)
Relationship status	
Husband	8 (7.3)
Wife	18 (16.4)
Son/Daughter	14 (12.7)
Brother	24 (21.8)
Sister	11 (10.0)
Mother	16 (14.5)
Father	11 (10.0)
Other	8 (7.3)
Duration of care (years)	$3.24 \pm 1.40$

SCI: spinal cord injury.

Figure 1 were significant and in the expected direction, ranging from 0.24 to 0.75 (Figure 1).

#### Face and content validity

Two ambiguous items (items no. 17 and 19) in face validity phase were revised and cleared in expert panel meeting. Then, the questionnaire was returned to the caregivers for clarification and their final approvals were obtained. In terms of relevance, clarity, and simplicity, a CVR of over 0.7 was obtained for all items, except for item no. 19, which was 0.63. The results relating to the necessity of the CBS items indicated a content validity ratio above 0.7 for all items except item no.19 (CVR = 0.57). The value of CVI for the whole scale was 0.82.

### Reliability analysis

Table 2 shows Cronbach's  $\alpha$  coefficients of the CBS and its subscales. All subscales of CBS revealed acceptable internal consistency (0.698–0.740), except for environment (0.559). The two-week test-retest reliability of the CBS in 54 caregivers using ICC was within the acceptable (0.745-0.900) (Table 2).

## **Construct validity**

To examine the construct validity of the CBS, Pearson's correlation coefficients were calculated among CBS and the BDI-II and WHOQOL-BREF (Table 3). As expected, the CBS and its subscales were positively correlated with the BDI-II (rs ranging from 0.437 to 0.646). The general strain and environment domains of CBS had the highest (r = 0.646) and lowest (r = 0.437) significant correlation with BDI-II scores.

CBS was negatively correlated with the WHOQOL-BREF and its subscales (rs ranging from -0.284 to -0.645). The highest significant correlation was found between the general strain domain of CBS with the physical domain of WHOQOL (r=-0.645) and the lowest significant correlation was related to the isolation domain of CBS and environment of WHOQOL (r=-0.284) (Table 3).

q=question e=error

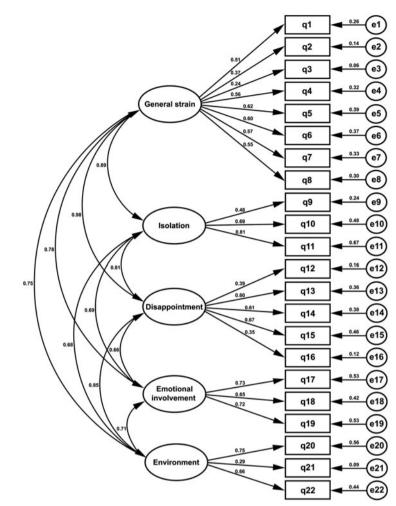


Figure 1. Confirmatory factor analysis of the CBS of caregivers of patients with SCI (n = 110).

Table 2. Descriptive statistics and reliability analysis of the CBS in caregivers of patients with SCI.

		Descriptive statistics			
	Number of items	Cronbach's $\alpha$ N = 110	ICC N = 54	Mean	SD
General strain	8	0.740	0.871	19.7	4.5
Isolation	3	0.698	0.900	6.1	2.1
Disappointment	5	0.704	0.838	12.7	2.9
Emotional involvement	3	0.755	0.745	5.7	1.7
Environment	3	0.559	0.832	7.3	1.9

SCI: spinal cord injury;CBS: Caregiver Burden Scale.

## **Discussion**

The first aim of this study was to translate the English version of the CBS into Persian while maintaining cultural and linguistic equivalence to Iranian culture. An expert panel session attended by rehabilitation specialists and our consultation with the original developer of the scale contributed to the final consensus and adoption of the translated version. An investigation in the psychometric features of this scale in terms of its validity and reliability showed it can effectively assess the perceived level of burden among caregivers of SCI patients.

To the best of our knowledge, this is the first study evaluating the factor structure of CBS in caregivers of patients with SCI. The five-factor model of CBS was tested. In general, the results of the

confirmatory factor analysis supported the original five-factor model of CBS proposed by Elmståhl et al. [19] The goodness of fit indices were in the acceptable range. All factor loadings were high, except for item number 3, which had shown low loadings on general strain factor and also decreased its internal consistency. These results indicate that some modifications for item 3 may be needed in the CBS to yield better factor structure. A cross-cultural difference may contribute to this result.

According to the results of the face and content validity, Persian CBS has acceptable CVR and CVI. Although the scores of simplicity, relevancy, necessity, and clarity were acceptable for item 19, its scores were relatively lower than those of other items, which may be due to the close meanings of "embarrassed" in item 19 and "ashamed" in item 17 in Persian. Additional explanations in parentheses have brought to ensure that respondents fully understand the subtle differences not evident within the translated version.

ICC obtained for the assessment of repeatability in Persian CBS indicated that all domains of CBS had excellent values and the scale had acceptable repeatability. The results related to reliability (test-retest) of this study were consistent with the results of other versions of this scale.[19,20]

In order to evaluate the other aspect of reliability, internal consistency was investigated among the items. Findings of this study indicate satisfactory Cronbach's α in all categories except environment. The results related to this category were similar to the results of the English version of this scale, in which Cronbach's  $\alpha$ 

Table 3. Pearson's correlation coefficients between CBS and the BDI-II and WHOQOL-BREF in caregivers of patients with SCI (n = 110).

		WHOQOL-BREF			
	BDI	Physical health	Psychological	Social relationships	Environment
General strain	0.646 <sup>a</sup>	-0.645 <sup>a</sup>	-0.563 <sup>a</sup>	-0.411 <sup>a</sup>	$-0.425^{a}$
Isolation	0.499 <sup>a</sup>	$-0.422^{a}$	$-0.355^{a}$	$-0.296^{a}$	$-0.284^{a}$
Disappointment	0.560 <sup>a</sup>	$-0.543^{a}$	$-0.492^{a}$	$-0.337^{a}$	$-0.412^{a}$
Emotional involvement	0.553 <sup>a</sup>	$-0.487^{a}$	$-0.427^{a}$	$-0.344^{a}$	$-0.359^{a}$
Environment	0.437 <sup>a</sup>	−0.481 <sup>a</sup>	$-0.440^{a}$	-0.331 <sup>a</sup>	$-0.394^{a}$

. SCI: spinal cord injury;CBS: Caregiver Burden Scale;BDI-II: Beck Depression Inventory;WHOQOL-BREF: World Health Organization's Quality of Life Questionnaire.

for environment was reported to be lower than the acceptable value (0.7). Lower Cronbach's  $\alpha$  for environment in this study may be due to the urban context and structure in Iran. The lack of specific therapeutic protocol after the discharge of the patient and the lack of formal adaptation of the environment require families to ultimately solve accessibility problems. Furthermore, residential areas in Iran vary in terms of proper support, accessible public transportation systems, and access to social and medical services, which means that participants in this study may come from very different situations. Also, one of the reasons for low Cronbach's  $\alpha$ is the small number of items in this domain.

As expected, construct validity analyses indicated that participants with high caring burden have low perceived quality of life and higher depression rates. Moderate to high significant negative correlation was observed in all domains of CBS and WHOQOL scales. The general strain domain of the CBS and the physical domain of WHOQOL demonstrated the highest negative significant correlation, while the isolation domain of CBS and the environment domain of WHOOOL had the lowest correlation. These results are consistent with the findings of other studies conducted with the aim of finding relationships between burden of care and quality of life in the caregiver population.[4,6,10,29] Their results revealed a negative correlation between quality of life and burden of care. In other words, as the burden of care increases, one's perceived quality of life decreases.

The Brazilian version of CBS in Rheumatoid Arthritis patients and their caregivers has indicated a significant negative relationship between the perceived quality of life and caregiver burden, consistent with the construct validity results in the present study.[20] In Iran, caregivers experience greater burden than in other developed countries, resulting in a significantly lower perceived quality of life largely due to lack of sufficient support and adequate municipal services for patients and their caregivers (training of caring role, public transportation system, social and, medical services).

Another scale used for examining construct validity with CBS was BDI. Our findings indicated a significant positive relationship between all domains of Persian CBS and BDI-II scores. The "general strain" domain had a high correlation and other domains had a moderate correlation with the depression survey. These results were consistent with the study conducted by Richard et al., which suggested that a decrease in engagement in social activities could consequently lead to more involvement of caregivers in caring task, experiencing less positive emotions and an increased occurrence of depression-related behaviors.[30] The previous studies have correlated depression and stress resulting from care services and living with a fully dependent person, too.[31] This study has several limitations that should be noted. First, the sample size was relatively low. Although sample size met the minimum requirements suggested by the Tabachnick and Fidell, [32]

a larger sample size would provide more valid and reliable results. Second, our study was conducted only in one center via convenience sampling method. However, the data were from recruitment center that attract patients with SCI from many different cities and just a small percentage of them were from Tehran. Despite many studies being conducted on caregivers of SCI patients in recent years, there is no assessment tool to specifically assess burden among Persian-speaking caregivers. The present study as the first research on caregivers of patients with SCI that showed good to excellent psychometric properties of the Persian version of CBS and that can be used as a special assessment tool to assess burden among Persian-speaking caregivers of patient with SCI.

#### Conclusion

The results of the present study indicates that CBS is a valid and reliable tool for assessing burden in Iranian caregivers of patients with SCI and may serve as an appropriate tool for specifically measuring burden in this group of caregivers in future studies.

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#### **Disclosure statement**

There is no conflict of interest.

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