



Translation, Face and Content Validity of Burden Scale for Family Caregivers

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Abstract

Background: Informal caregivers who give regular care to their relative, needing help for a time, are at risk of many difficulties such as financial dependency, anger, wandering, social problems and communication problems. The purpose of our study is to translate and validate a Persian version of “burden scale for family caregivers-short (BSFC-s)” to measure the burden of informal caregivers.

Methods: The BSFC-s was translated into Farsi by the world health organization (WHO) method. Content validity was evaluated by 15 experts in the field of occupational therapy and physical therapy using Lawshe’s method. A total of 11 caregivers of stroke families’ patients scored each item for face validity.

Results: The results indicated that BSFC-s has good face validity. The impact factor was between 2.94 and 4.14. No item had a content validity index (CVI) below 0.79 and based on the Lawshe’s method, the items’ content validity ratio (CVR) was above 0.49.

Conclusions: The BSFC-s was translated into Persian and its face as well as content validity were acceptable. Nevertheless, further studies are needed to evaluate its reliability and validity.

Keywords: Stroke, Burden of Disease, Cost of Disease, Validity

1. Background

According to the literature, over the years, family caregivers have reliably shown increased caregiver burden related to diminished mental and physical health (1, 2). Relatives of patients who are chronically ill carry a heavy burden, particularly if the patient lives at home (3). The burden of disease exists in all societies and has a great impact on the family and health system (4). The burden of caregiving is the negative effect of the disease on caregivers and involves many mental and physical difficulties in taking care of the patient.

Caring for the patient can lead to a range of mental and physical symptoms for the caregiver (5-7). Some studies claim that care can cause many negative problems like increased financial dependency, anger, wandering, fall, social problems, and decreased self-efficacy (8-10). Stroke not only changes the affected person’s life, but also alters the caregiver’s personal life. A caregiver of a stroke patient performs a variety of cares for his patient, ranging from physical assistance to mental support (11). According to statistics, about 80% of stroke patients return home after admission and about half of them need temporary or permanent help at home (12).

Until lately, nearly most health care providers and policymakers had the perception that long-term care is provided in nursing homes. Nevertheless, the statistics contradict this opinion. A total of 80% of patients who receive care rely exclusively on informal caregivers - individuals who give routine care to closely related people needing aid for a time and who do not provide care as an occupation- (13).

One of the questionnaires that can assess the informal caregivers’ burden is “burden scale for family caregivers”. The questionnaire was developed in 1993 by Grasel and colleagues in Germany and is used to measure the burden of care on the affected families (14). Burden scale for family caregivers (BCFC) gives fundamental data about the negative aspects of providing care and how providing care influences the caregiver’s wellbeing (15). The BSFC is advantageous as it can be utilized as a clinical instrument (15) for evaluating the care providing circumstance, recognizing regions of concern. It can also be used for research purposes (16-19) for observational investigations or as a result measure in clinical trial studies.

This instrument has been developed by gathering information from caregivers through qualitative interviews, followed by expert panels and pilot studies (15). In 2014,

Graessel and colleagues developed a short version of the burden scale for family caregivers (BSFC-s), which consists of 10 questions with the highest discriminatory power from the 28-item BSFC long version (20). With only 10 items, BSFC-s requires a rather short time for completion. If we define feasibility as the ratio of unanswered questions to answered questions and the average time for filling a questionnaire (21), BSFC-s has good feasibility.

As the burden of caregivers has many aspects, the burden-assessment tools have different methods for evaluating the burden. Some tools divide the burden into different subsets and measure the burden in each subset (22). Another method is to designate one "total" score for the burden. BSFC measures burden by a total score (15).

This study was conducted with regards to the importance of measuring caregiver burden in practice and research as well as lack of a questionnaire to assess the burden of informal caregivers in Farsi exclusively.

2. Methods

Before starting the process, a written permission was taken from the developer to start the process. After taking the permission, the ethics code was taken from the Ethics Committee of Iran University of Medical Sciences to begin the study.

The BSFC-s is available in 20 languages including French, Finnish, Greek, English, Chinese, German etc. We had access to a skilled English translator; the translation was based on the English version, which was approved by the original author.

2.1. Translation

According to the original developer's recommendation, the WHO methodology (23) was used to translate the questionnaire.

In the first stage, 2 translators who were fluent in Farsi translated the questionnaire. They translated the questionnaire from English to Farsi. They had a history of questionnaire translation, however, they did not have a familiarity with this questionnaire. The translators were asked to avoid word-by-word translating and rely more on the conceptual translation. In addition, they tried to make the concepts as simple, clear, and concise as possible. Given that the target audience of the tool is ordinary people, not professionals, they avoided using specialized terms. The translators tried to avoid the use of sensitive sentences as much as possible. In the next step, a bilingual (in English and Persian) expert panel convened. The expert panel questioned some phrases and words, with some alternative words suggested. In addition, inadequate expressions

of the translation and deviations between the translation and original text were resolved.

2.2. Face Validity

At this point, a questionnaire was given to 11 caregivers of stroke patients to evaluate the face validity. Before starting the process, they signed informed consent. They had no cognitive problems and were fluent in reading and writing in Farsi. The subjects were chosen from 3 different clinics from 3 different areas of Tehran. The caregivers answered each of the 10 questionnaire items based on relevancy, clarity, and simplicity on a five-scale Likert form.

The impact score was used to evaluate the face validity. As mentioned previously, the participants could give each item a score between 1 to 5. First, the mean score for each item was calculated by summing up all participant scores to an item and then dividing the result to the participants' number, which was 11. Second, each items' mean score was multiplied by the percentage of participants who gave 4 or 5 to each item. For example, if the mean score for an item was 4.1 and the percentage of participants who gave 4 or 5 to that item was 80%, the impact score would be $4.1 \times 0.8 = 3.28$. If the impact score of an item was equal or more than 1.5, that item was acceptable (24).

2.3. Content Validity

The content validity was calculated based on content validity index (CVI) and content validity ratio (CVR) method. CVR or Lawshe's method is a quantitative method for determining the content validity and is widely accepted. In this method, a group of experts is asked to comment on the importance and necessity of each question. CVI or Waltz and Bausell method is an approach to assess validity. In this method, each item needs a score more than 0.79 to be accepted (25).

To this end, the questionnaire was provided to 13 occupational therapists and 2 physiotherapists who preferably had 5 years of experience in evaluating and treating patients. From these 15 experts, 8 were the PHD faculty members, 4 were PhD students, and 3 had a master's degree.

3. Results

There was a good agreement for translation of items 2, 6, 7, 9, and 10 between translators and expert panel. In other questions, some changes were made based on caregivers' comments, expert panel, and translators' opinions. The caregivers' demographic information is presented in Table 1.

The result of face validity is shown in Table 2. Caregivers who consist of 6 males and 5 females scored each

Table 1. Demographic Information of the Caregivers

Variables	No.	%
Gender		
Male	6	54
Female	5	46
Marital status		
Single	4	36
Married	7	64
Education		
Elementary	2	22
High school	5	45
Academic	4	36
Family relation		
Wife	2	22
Husband	3	33
Brother	1	11
Son	2	22
Daughter	3	33

item for its face validity. Based on our method, for accepting an item, its score should have been being higher than 1.5.

Table 3 represents the CVR and CVI method. Our sample included 15 individuals, therefore, based on Lawshe's method, a score of 0.49 or above is needed to verify each item's CVR, while 0.79 or more is required for CVI.

4. Discussion

The burden of care is one of the factors that affect the patient and his or her family at various stages of life. Notably, it is better for the therapist not to focus on his interventions only on the patient (26). Given the importance of family in the treatment process (27), it is better to hold a holistic approach and consider the negative factors that affect the patients' family. Due to the lack of a scale in Farsi that measures the burden of informal caregivers exclusively, the purpose of this study was to translate BSFC-s questionnaire into Farsi and examine its face and content validity.

Brogaard and colleagues translated and validated BSFC into Danish in 2013. They found conceptual differences owing to the terms 'caregiving', 'caregiver', and 'care'. As these words had no direct translation into Danish, they used the conceptual translation for these words. After qualitative face validity discussion, some changes were made and the Danish version was approved (28).

The translation process was carried out based on the WHO protocol. The translation was completed successfully. Most of the conceptual differences in the translation were due to the presence of words such as 'Burden' and 'Care'. It seems that the word 'Burden' has no exact synonym in Persian. For this reason, translators used a two-word expression to convey its meaning. Due to the importance of conceptual translation and avoiding literal translation, some terms such as "I feel torn between" and "feel like myself" were translated into synonymous Farsi expressions.

In assessing the face validity, all items received an acceptable score. This means that for the majority of the sample group, the items were simple and important. One of the reasons that can be mentioned for accepting all the questions is that the burden of responsibility is a universal issue (29). In every society, people with disabilities need care and attention; this care brings pressure to the family. Among the questions, the 5th question, which was about financial issues, got a lower score than the other items. One reason can be the existence of a belief in some caregivers that financial issues should not affect the care of the patient.

Content validity results indicated that all items had high content validity and there was no item that did not obtain the required score. This could be expected, as the translated questionnaire was a short version, and these 10 items were selected by the factor analysis of 28 items of the original questionnaire. These 10 items had more distinguishing power than other items.

Study limitations include lack of cooperation of some of the caregivers and difficulty in coordinating the time of meetings. It is recommended for future studies to validate the scale in other populations and compare the results.

4.1. Conclusion

In general, this questionnaire has a proper face and content validity. To our knowledge, there is no similar test in Farsi that can measure the burden of care on the informal caregivers exclusively. Therefore, the use of the Farsi version of the BCFC-s is recommended as a valid tool. This tool will be able to meet the clinical and research needs of researchers, professionals, and therapists.

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Table 2. Face Validity Results

Question	Impact Score
My life satisfaction has suffered because of the care.	3.12
I often feel physically exhausted.	4.14
From time to time I wish I could “run away” from the situation I am in.	3.47
Sometimes I don’t really feel like “myself” as before.	3.12
Since I have been a caregiver my financial situation has decreased.	2.94
My health is affected by the care situation.	4.14
The care takes a lot of my own strength.	3.32
I feel torn between the demands of my environment (such as family) and the demands of the care.	3.12
I am worried about my future because of the care I give.	3.64
My relationships with other family members, relatives, friends, and acquaintances are suffering as a result of the care.	3.44

Table 3. Content validity Index (CVI) and Content Validity Ratio (CVR)

Questions	CVR	CVI
My life satisfaction has suffered because of the care.	1	0.93
I often feel physically exhausted.	1	0.93
From time to time I wish I could “run away” from the situation I am in.	1	1
Sometimes I don’t really feel like “myself” as before.	0.86	0.86
Since I have been a caregiver my financial situation has decreased.	1	0.93
My health is affected by the care situation.	1	0.86
The care takes a lot of my own strength.	0.73	0.86
I feel torn between the demands of my environment (such as family) and the demands of the care.	1	0.86
I am worried about my future because of the care I give.	0.73	0.93
My relationships with other family members, relatives, friends, and acquaintances are suffering as a result of the care.	0.86	1

References

- Schulz R, Tompkins CA, Rau MT. A longitudinal study of the psychosocial impact of stroke on primary support persons. *Psychol Aging*. 1988;3(2):131-41. doi: 10.1037/0882-7974.3.2.131. [PubMed: 3268251].
- Denno MS, Gillard PJ, Graham GD, DiBonaventura MD, Goren A, Varon SF, et al. Anxiety and depression associated with caregiver burden in caregivers of stroke survivors with spasticity. *Arch Phys Med Rehabil*. 2013;94(9):1731-6. doi: 10.1016/j.apmr.2013.03.014. [PubMed: 23548544].
- Rosland AM, Piette JD. Emerging models for mobilizing family support for chronic disease management: a structured review. *Chronic Illn*. 2010;6(1):7-21. doi: 10.1177/1742395309352254. [PubMed: 20308347].
- Kassebaum NJ, Bertozzi-Villa A, Coggeshall MS, Shackelford KA, Steiner C, Heuton KR, et al. Global, regional, and national levels and causes of maternal mortality during 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet*. 2014;384(9947):980-1004. doi: 10.1016/S0140-6736(14)60696-6. [PubMed: 24797575].
- Pinquart M, Sorensen S. Correlates of physical health of informal caregivers: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci*. 2007;62(2):P126-37. doi: 10.1093/geronb/62.2.P126. [PubMed: 17379673].
- Mills PJ, Ancoli-Israel S, von Kanel R, Mausbach BT, Aschbacher K, Patterson TL, et al. Effects of gender and dementia severity on Alzheimer’s disease caregivers’ sleep and biomarkers of coagulation and inflammation. *Brain Behav Immun*. 2009;23(5):605-10. doi: 10.1016/j.bbi.2008.09.014. [PubMed: 18930805].
- Garlo K, O’Leary JR, Van Ness PH, Fried TR. Burden in caregivers of older adults with advanced illness. *J Am Geriatr Soc*. 2010;58(12):2315-22. doi: 10.1111/j.1532-5415.2010.03177.x. [PubMed: 21087225].
- Rabinowitz YG, Mausbach BT, Gallagher-Thompson D. Self-efficacy as a moderator of the relationship between care recipient memory and behavioral problems and caregiver depression in female dementia caregivers. *Alzheimer Dis Assoc Disord*. 2009;23(4):389-94. doi: 10.1097/WAD.0b013e3181b6f74d. [PubMed: 19935146].
- Stoltz P, Uden G, Willman A. Support for family carers who care for an elderly person at home - a systematic literature review. *Scand J Caring Sci*. 2004;18(2):111-9. doi: 10.1111/j.1471-6712.2004.00269.x. [PubMed: 15147473].
- Azad A, Hassani Mehraban A, Mehrpour M, Mohammadi B. Clinical assessment of fear of falling after stroke: validity, reliability and responsiveness of the Persian version of the Fall Efficacy Scale-International. *Med J Islam Repub Iran*. 2014;28:131. [PubMed: 25694989].
- Vincent C, Desrosiers J, Landreville P, Demers L, Brad group . Burden of caregivers of people with stroke: evolution and predictors.

- Cerebrovasc Dis.* 2009;**27**(5):456–64. doi: [10.1159/000210092](https://doi.org/10.1159/000210092). [PubMed: [19329849](https://pubmed.ncbi.nlm.nih.gov/19329849/)].
12. Opara JA, Jaracz K. Quality of life of post-stroke patients and their caregivers. *J Med Life.* 2010;**3**(3):216–20. [PubMed: [20945810](https://pubmed.ncbi.nlm.nih.gov/20945810/)].
 13. Gillen G. *Stroke Rehabilitation: A Function-based Approach.* 2015.
 14. Grasel E. Somatic symptoms and caregiving strain among family caregivers of older patients with progressive nursing needs. *Arch Gerontol Geriatr.* 1995;**21**(3):253–66. doi: [10.1016/0167-4943\(95\)00660-D](https://doi.org/10.1016/0167-4943(95)00660-D). [PubMed: [15374201](https://pubmed.ncbi.nlm.nih.gov/15374201/)].
 15. Gräsel E, Chiu T, Oliver R. *Development and validation of the Burden Scale for Family Caregivers (BSFC).* Toronto, Canada: Comprehensive Rehabilitation and Mental Health Services; 2003.
 16. Boots LM, de Vugt ME, van Knippenberg RJ, Kempen GI, Verhey FR. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry.* 2014;**29**(4):331–44. doi: [10.1002/gps.4016](https://doi.org/10.1002/gps.4016). [PubMed: [23963684](https://pubmed.ncbi.nlm.nih.gov/23963684/)].
 17. Schaller S, Marinova-Schmidt V, Setzer M, Kondylakis H, Griebel L, Sedlmayr M, et al. Usefulness of a Tailored eHealth Service for Informal Caregivers and Professionals in the Dementia Treatment and Care Setting: The eHealthMonitor Dementia Portal. *JMIR Res Protoc.* 2016;**5**(2). e47. doi: [10.2196/resprot.4354](https://doi.org/10.2196/resprot.4354). [PubMed: [27050401](https://pubmed.ncbi.nlm.nih.gov/27050401/)].
 18. Bibl M, Mollenhauer B, Esselmann H, Lewczuk P, Klafki HW, Sparbier K, et al. CSF amyloid-beta-peptides in Alzheimer's disease, dementia with Lewy bodies and Parkinson's disease dementia. *Brain.* 2006;**129**(Pt 5):1177–87. doi: [10.1093/brain/awl063](https://doi.org/10.1093/brain/awl063). [PubMed: [16600985](https://pubmed.ncbi.nlm.nih.gov/16600985/)].
 19. Krug K, Miksch A, Peters-Klimm F, Engeser P, Szecsenyi J. Correlation between patient quality of life in palliative care and burden of their family caregivers: a prospective observational cohort study. *BMC Palliat Care.* 2016;**15**:4. doi: [10.1186/s12904-016-0082-y](https://doi.org/10.1186/s12904-016-0082-y). [PubMed: [26767785](https://pubmed.ncbi.nlm.nih.gov/26767785/)].
 20. Graessel E, Berth H, Lichte T, Grau H. Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC Geriatr.* 2014;**14**:23. doi: [10.1186/1471-2318-14-23](https://doi.org/10.1186/1471-2318-14-23). [PubMed: [24555474](https://pubmed.ncbi.nlm.nih.gov/24555474/)].
 21. Bouwmans C, De Jong K, Timman R, Zijlstra-Vlasveld M, Van der Feltz-Cornelis C, Tan Swan S, et al. Feasibility, reliability and validity of a questionnaire on healthcare consumption and productivity loss in patients with a psychiatric disorder (TiC-P). *BMC Health Serv Res.* 2013;**13**:217. doi: [10.1186/1472-6963-13-217](https://doi.org/10.1186/1472-6963-13-217). [PubMed: [23768141](https://pubmed.ncbi.nlm.nih.gov/23768141/)].
 22. Visser-Meily JM, Post MW, Riphagen J, Lindeman E. Measures used to assess burden among caregivers of stroke patients: a review. *Clin Rehabil.* 2004;**18**(6):601–23. doi: [10.1191/0269215504cr776oa](https://doi.org/10.1191/0269215504cr776oa). [PubMed: [15473113](https://pubmed.ncbi.nlm.nih.gov/15473113/)].
 23. World Health Organization. *Process of translation and adaptation of instruments.* World Health Organization; 2016. Available from: who.int/substance_abuse/research_tools/translation/en.
 24. Weller K, Groffik A, Magerl M, Tohme N, Martus P, Krause K, et al. Development, validation, and initial results of the Angioedema Activity Score. *Allergy.* 2013;**68**(9):1185–92. doi: [10.1111/all.12209](https://doi.org/10.1111/all.12209). [PubMed: [23919330](https://pubmed.ncbi.nlm.nih.gov/23919330/)].
 25. Lawshe CH. A quantitative approach to content validity. *Pers Psychol.* 1975;**28**(4):563–75. doi: [10.1111/j.1744-6570.1975.tb01393.x](https://doi.org/10.1111/j.1744-6570.1975.tb01393.x).
 26. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology.* 2010;**19**(10):1013–25. doi: [10.1002/pon.1670](https://doi.org/10.1002/pon.1670). [PubMed: [20014159](https://pubmed.ncbi.nlm.nih.gov/20014159/)].
 27. Miller EL, Murray L, Richards L, Zorowitz RD, Bakas T, Clark P, et al. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. *Stroke.* 2010;**41**(10):2402–48. doi: [10.1161/STR.Ob013e3181e7512b](https://doi.org/10.1161/STR.Ob013e3181e7512b). [PubMed: [20813995](https://pubmed.ncbi.nlm.nih.gov/20813995/)].
 28. Brogaard T, Neergaard MA, Guldin MB, Sokolowski I, Vedsted P. Translation, adaptation and data quality of a Danish version of the Burden Scale for Family Caregivers. *Scand J Caring Sci.* 2013;**27**(4):1018–26. doi: [10.1111/j.1471-6712.2012.01092.x](https://doi.org/10.1111/j.1471-6712.2012.01092.x). [PubMed: [23072710](https://pubmed.ncbi.nlm.nih.gov/23072710/)].
 29. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA.* 2014;**311**(10):1052–60. doi: [10.1001/jama.2014.304](https://doi.org/10.1001/jama.2014.304). [PubMed: [24618967](https://pubmed.ncbi.nlm.nih.gov/24618967/)].