Original Article

Development and Validation of "Caregiver Burden Scale-Indian Population"

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Abstract

Background: Caregiver burden is always a neglected domain, and assessment of burden with available instruments developed in one country is neither reliable nor valid because of different cultural, ethical, religious, and other personal values. This study is an attempt to develop an appropriate instrument which can assess the burden on caregivers from the Indian subcontinent and other Asian countries. This work is an attempt to develop and standardization of CBS-IP using content and construct validity. **Methods:** The study was conducted with a total of 125 (55 – initial interview + 25 – pilot study + 45 – construct validity) caregivers of individual with chronic neurologically ill patients. Content and construct validation was performed as follows: (1) search of relevant electronic databanks and use of experts and caregivers' opinions to prepare appropriate content, review, and correction of the content through discussions with experts. (2) Content validity has been established by computing content validity index (CVI). (3) Construct validity has been established by correlating (Pearson's-r) with another standardized instrument (Eysenck Personality Questionnaire-Revised) using multitrait procedure. **Results:** Using CVI procedure, scale-level CVI (S-CVI) universal agreement is 0.889; S-CVI average is 0.898. The item-level CVI is 0.90. The Pearson product-moment correlation coefficient (r) was obtained by comparing caregiver burden scale-Indian population (CBS-IP) total with extraversion, $r = -0.440$, $n = 45$, $P = 0.002$; CBS-IP total with neuroticism, $r = 0.228$, $n = 45$, $P = 0.132$; and CBS-IP total with psychoticism, $r = -0.011$, $n = 45$, $P = 0.942$. **Conclusions:** We believe that the new tool CBS-IP is a good empirical instrument for evaluating stressors on informal caregivers in India and possibly in some other countries in Asia.

Keywords: *Construct validity, content validity, neurologically ill*

Introduction

The treatment outcome and the patients' need for support of family represent the caregivers' significant and essential role.[1] Even though a number of instruments are available for the caregivers, the assessment of burden has become a challenging task for most researchers because cultural, ethical, religious, and other personal values may influence perceptions of meaning and consequences of burden.[2,3] Recent researches have highlighted about the role of caregivers and the burden involved in it. The emphasis on rehabilitation has also shifted from mere patient-focused approach to a combined patient- and caregiver-focused approach considering the significant role played by caregivers.[4,5] In essence, the meaning of burden to various cultures needs to be determined. Therefore, an attempt is made to develop an appropriate instrument which can assess the burden on caregiver from the Indian subcontinent and other Asian countries matching with Indian culture and sociodemographic variables.

In this study we aimed to develop a valid questionnaire suitable for the Indian culture, which measures the stress mounted on primary caregivers of neurologically ill individuals.

Methods

The study is conducted between December 2013 and September 2015 at the Occupational Therapy Department of Swami Vivekananda National Institute of Rehabilitation Training and Research (SVNIRTAR), Odisha, India. In November 2013, the synopsis for research proposal is presented in front of ethical committee and got approval to continue the thesis.

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During this period, a total of 264 caregivers of individual with chronic stroke, head injury, and spinal cord injury (SCI) attending the services of our rehabilitation hospital were identified and invited to the department for interviews. A total of 125 (55 – initial interview +25 – pilot study +45 – construct validity) caregivers reported for the interview. With confidence level of 95%, confidence interval 8.59, and unlimited population size, our requirement for sample size was 131, but due to unavailability of individuals and lack of time, the data of 125 subjects used for statistical analysis.

Criteria for selection of potential participants

Inclusion

- Informal caregiver (nonpaid)
- Caregiving duration more than 6 months.

Exclusion

- Caregivers must not suffering from any major disabling condition which indirectly adds on to the burden of Care giving.

Criteria for selection of experts for peer review

Inclusion

- Any rehabilitation professional with minimum 5-year experience in treatment and rehabilitation of neurologically Ill patients.

Exclusion

- None

Statement of purpose of Caregiver Burden Scale-Indian Population

"The instrument to be constructed will assess the caregivers' burden related to physical, economical, time, social, and psychological domains of caregiving for neurologically ill patients."

Tool used

The Eysenck Personality Questionnaire-Revised (EPQ-R) scales: EPQ-R measures three major dimensions of personality that account for most of the variance in personality of an individual. EPQ-R is highly validated and reliable scale that has been used in this study.[6,7]

Development of the instrument

First phase: Qualitative phase

Stepwise ethnographic exploration is an iterative process that enabled us to derive items (questions) that were contextual and reflected not the opinions of the researchers but that of the caregivers themselves.

An initial unstructured interview was conducted on 15 caregivers of individual with chronic neurologically illness. All interviews were carried out in the local language Oriya and national language Hindi. We (researcher and guide) met regularly and exchanged experiences with the aim of arriving at a consensus on the various domains of burden such as physical, financial, time, and psychosocial aspects and social relations. Based on these unstructured interviews, a semi-structured interview guide was prepared which enabled the interviewers to be more focused on specific domains for caregiving.

With the help of this interview guide, semi-structured interview was conducted on a fresh sample of 40 caregivers. At the end of this stage, we once again met with rehabilitation experts and research guide to discuss our findings. When we found that our information was becoming repetitive, no new issues were emerging and that all the respondents had endorsed the domains of burden, and we decided to stop doing further interviews. This endorsement during successive interviews helped us to establish the relevance of these domains to the assessment of burden.

Second phase: Development of the structured instrument

This phase starts with the process of itemization or framing the questions that would constitute the instrument. The written transcripts of the interviews were carefully studied for framing items reflecting the views of caregivers. Care was taken to use simple language that could be easily understood by the common man. About 27 such questions were initially generated within domains of psychological, physical, economical, time, and social and 2 descriptive questions related to satisfaction and support the caregiver receiving from health professional. The deletion of ambiguously worded, repetitive, and irrelevant questions resulted in a 25-item questionnaire. The draft instrument thus established was then subjected to the assessment of its psychometric properties.

Third phase: Quantitative phase-face validity, content validity, and construct validity

This phase starts with selection of panel of experts those working in the field of rehabilitation dealing with persons with neurologically illness and their caregivers.

- Pilot study: The scale was initially administered to 25 caregivers that met the sample criteria and determined that the questions in the scale were found clear and comprehensible by CG, and a decision was made to use the scale further for its validity and reliability
- Face validity: The draft instrument was given to a team of rehabilitation and their opinions were sought, whether at face value, the instrument appeared to be assessing the desired qualities. All the rehabilitation professionals agreed with respect to the relevance of the items in measuring burden
- Content validity of the scale was established through a logical process wherein we first selected a panel

of experts consists of content expert and lay experts. This helped us to determine whether the CBS-IP scale is well-constructed and suitable for psychometric testing. We contacted every member of expert panel through E-mail or telephone call for soliciting their participation. Ones the expert confirms for their participation, we make available them with a cover letter, response form, and self-addressed stamped return envelope.

We received ample amount of suggestions for Caregiver Burden Scale-Indian Population (CBS-IP) from our experts on different issues which help us to improve quality of the scale.

Finally, we concluded with 25 items (5 items in each domain) rated on a 4-point scale with scoring of 1–4. The responses were "not at all, sometimes, often, and always." The order of the responses was varied according to the questions framed on the scale.

Construct validity was established by correlating the new scale (CBS-IP) with EPQ-R, with the assumption that the caregivers having significant burden must be having positive correlation with neuroticism personality (convergent validity) and negative correlation with extraverted personality (divergent validity).[8]

Fourth phase: Data collection and analysis

A total of 45 caregivers accepted their participation in the study through signing consent form, and both CBS-IP and EPQ-R were used by occupational therapists on agreed individuals with purpose of construct validity.

Results

Data obtained were analyzed using the Statistical Package for the Social Science (SPSS) software version 16, Manufactured by IBM Corporation Business analytics software portfolio. Descriptive statistics were used to analyze participant's characteristic using numeric and percentile tests. Pearson correlation coefficient is used to calculate construct validity of the scale, where the two instruments were found is significant as per the expectation. Content validity index (CVI) is calculated though simple descriptive calculation using Microsoft Excel.

Demographics and descriptive analysis

A total of 45 caregivers were participated in this study; 25 were male and 20 were female, with a mean age of 38.7 years (standard deviation [SD] =13.020); 34 (75.6%) married and 11 (24.4%) unmarried; and education level of caregivers is as follows: 12 – primary, 12 – matric, 13 – intermediate, and 8 is graduated in different participants. Regarding the relationship to the individual with PWD, 7 were husband, 10 – wife, 3 – brother, 2 – sister, 7 – son, 3 – daughter, 7 – mother, and 6 – father. With respect to the type of family, 17 were belonged to joint family (37.8%) and 28 is nuclear family (62.2%). Out of 45, 18 (40%) caregivers are from urban and 27 (60%) were belonged to rural population. Caregiving duration mean is 13.51 months (SD = 10.48) and range is from 6 to 72 months. The number of years of education mean is 10.13 (SD = 3.539), median is 10, and range is 5–15.

Item selection and face validity

The finalized CBS-IP comprises 25 items. The face validity of the CBS-IP items was judged by professionals who had experience in dealing with caregivers and caring for patients with neurological illness such as SCI, stroke, and head Injury. Out of 11 experts, 9 expressed scales are face valid and 2 experts suggested to reframe the few questions and to remove descriptive questions.

Content validity

We got feedback from 11 experts (2 alert caregivers and 9 content experts) on relevancy, clarity, and comprehensiveness of the 27 questions extracted from the literature review and initial brainstorming sessions with CGs [Table 1].

All expert rated every questions of the scale on 5-point ordinal scale (completely agree – 1, mostly agree – 2, somewhat agree – 3, slightly agree – 4, and do not agree at all – 5). To calculate item-level CVIs (I-CVIs), we dichotomize the score into 1 = relevant (completely agree – 1 and mostly agree – 2) and 2 = not relevant (somewhat agree – 3, slightly agree – 4, and do not agree at all – 5).

On the basis of expert's suggestions and rating for their agreement on the relevancy, clarity, and comprehensiveness of the 27 suggested questions, the final draft scale was prepared which included 25 questions. Computational procedures for scale-level CVI, which is used for the sake of clarity as the scale-level CVI/universal agreement (S-CVI/UA), are defined as "the proportion of items on an instrument that achieved a rating of 1or 2 by all the content experts". In CBS-IP out of 27 questions, only 3 questions (2, 18, and 24) received rating below significance (0.80), and S-CVI/UA is 0.889 (plausible). The S-CVI average (S-CVI/Ave) we calculated by three different methods as mentioned below. First by doing averages, the proportion of items rated relevant across experts. Thus, we calculated S-CVI/Ave as (0.88 + 0.85 + 0.92 + 0.81 + 0.81 + 1 + 0.77 + 0.96 + 0.92 + 0.96 + 1)/11 = 0.898. Second way is average the I-CVIs by summing them and dividing by the number of questions (0.91 + 0.72 + 0.91 + 1 + 1+……0.81)/27 = 0.90. Third is by counting the total number of "relevant=1" in the table; the number of questions rated relevant by experts combined, which is 268 and to then divided by the total number (297) of ratings: 268/297 = 0.90 [Table 1].

Table 1: Ratings on a 27- Item scale by Eleven Experts for Content Validity Index

Item	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Expert 6	Expert 7	Expert 8	Expert 9	Expert 10	Expert 11	No In agreement	Item CVI
1	1	2	1	1	1	1	1	1	1	1	1	10	0.91
2	1	1	1	2	2	1	2	1	1	1	1	8	0.72
3	2	1	1	1	1	1	1	1	1	1	1	10	0.91
4	1	1	1	1	1	1	1	1	1	1	1	11	1
5	1	1	1	1	1	1	1	1	1	1	1	11	1
6	1	2	1	1	1	1	1	1	2	1	1	9	0.81
7	1	1	1	2	1	1	1	1	1	1	1	10	0.91
8	1	1	1	1	1	1	1	1	1	1	1	11	1
9	1	1	1	1	1	1	1	1	1	2	1	10	0.91
10	1	1	1	1	1	1	1	1	1	1	1	11	1
11	1	2	1	1	1	1	1	1	1	1	1	10	0.91
12	1	1	1	1	1	1	1	1	1	1	1	11	1
13	1	1	1	1	1	1	1	1	1	1	1	11	1
14	1	1	1	1	2	1	1	1	1	1	1	10	0.91
15	2	1	1	2	1	1	1	1	1	1	1	9	0.81
16	1	1	1	1	1	1	2	1	1	1	1	10	0.91
17	1	1	1	1	2	1	2	1	1	1	1	9	0.81
18	2	1	1	1	1	1	2	1	2	1	1	8	0.72
19	1	1	1	1	1	1	1	1	1	1	1	11	1
20	1	1	1	1	1	1	1	1	1	1	1	11	1
21	1	1	1	1	1	1	1	1	1	1	1	11	1
22	1	1	1	1	2	1	1	1	1	1	1	10	0.91
23	1	1	1	2	2	1	1	1	1	1	1	9	0.81
24	1	1	1	2	1	1	2	2	1	1	1	8	0.72
25	1	1	1	1	1	1	2	1	1	1	1	10	0.91
26	1	1	2	1	1	1	1	1	1	1	1	10	0.91
27	1	2	2	1	1	1	1	1	1	1	1	9	0.81
	24/27	23/27	25/27	22/27	22/27	27/27	21/27	26/27	25/27	26/27	27/27	Mean I-CVI	0.9
	0.88	0.85	0.92	0.81	0.81	1	0.77	0.96	0.92	0.96	1	S-CVI/UA	0.889
											S-CV/Av	286/297=0.90	

All three computations will always yield the same result. As described in literature,[9] it is best to conceptualize the S-CVI/Ave as the average I-CVI value because this puts the focus on average item quality rather than on an average performance by the experts.

Construct validity

A Pearson's product-moment correlation coefficient (r) was computed to assess the relationship between the total score of burden (CBS-IP total) and score of extraversion, neuroticism, and psychoticism from EPQ-R. CBS-IP correlated negatively with extraversion with value of $r = -0.440$, $n = 45$, $P = 0.002$. Positively correlation between CBS-IP total and neuroticism as $r = 0.228$, $n = 45$, $P = 0.132$ and negative correlation between CBS-IP total and psychoticism as $r = -0.011$, $n = 45$, $P = 0.942$ [Table 2].

Discussion

Given the paucity of multidimensional care burden scales in India, the present findings confirming the validity of the CBS-IP, a short multidimensional scale which measures 5 domains with 25 items, are significant. The distinctive feature in the development of the CBS-IP is the use of a combination of qualitative and quantitative methods. The "stepwise ethnographic exploration" involves a thorough conceptual mapping of the subject under study before establishing individual items. We believe that, by measuring both subjective and objective burdens, CBS-IP will be sensitive enough to detect major area of burden. In this study, views of 11 experts were obtained to determine whether the items of the scale content and composition are appropriate, given what is being measured for the Indian culture.

Content validity

Concordance of the expert views was assessed using CVI. I-CVI (mean of content validity of individual items) is 0.90, S-CVI/universal agreement is 0.889 (>0.80), S-CVI/average is 0.898, 0.90, and 0.90 with three different ways, and the average congruency percentage is 0.90 (>0.90) [Table 1]; as per literature, all three computations will always yield the same results. We think, however, that it is best to

Table 2 Correlation result between CBS-IP total and EPQ-R (Neuroticism, Psychoticism, Extraversion)

EPQ-R	CBS-IP total
Neuroticism	
Pearson correlation	0.228*
Sig. (2-tailed)	0.132
n	45
Psychoticism	
Pearson Correlation	-0.011
Sig. (2-tailed)	0.942
n	45
Extraversion	
Pearson Correlation	-0.440**
Sig. (2-tailed)	0.002
n	45

**Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed)

conceptualize the S-CVI/Ave as the average I-CVI value because this puts the focus on average item quality rather than on average performance by the experts. This result was interpreted as significant agreement by the experts with respect to the content of the scale.[9]

Construct validity

To establish construct validity, we use the multitrait procedure. This procedure allows for determination of the extent to which test correlates (convergent validity) with the related constraints and does not correlate (divergent validity) with constructs that are not related. These correlations are compared with those obtained between tests thought to measure different traits with a similar format.[10,11] In CBS-IP, the relationship between the CBS-Total and specific domains of EPQ-R with Pearson moment correlations were in the predicted direction and were significant. As mentioned in the Table 2. As expected CBS-Total correlates in positive (r = 0.228*) direction with Neuroticism, though not significantly. It could well imply that stress could be linked with some anxiety. It correlates near 0 (−0.011) with psychoticism which can be seen as unconventionality. Whether one feels least concerned about what the society think as conventional does not affect the way one perceives stress when required to take care of any specific person. CBS-Total score correlates negatively (r = −0.440) with extraversion as extraverted people go out more and manage to get more psychological and social support from outside [Table 2].

Benefits of caregiver assessment

Words by Lynn Feinberg emphasis on the importance of caregiver's assessment, "Caregivers who have their needs assessed often feel acknowledged, valued, and better understood by practitioners."[12] Ibrahim Obdalpur expressed "a face-to-face interview would be more suitable because of a more effective communication and better cooperation between the respondent and the questioner". We also recommend the professionals to use the CBS-IP, in an interview format to get an in-depth understating about the caregivers burden.[13] In addressing the clinical scenario, the majority of studies suggested that it would be beneficial for occupational therapist to provide occupational therapy intervention to the family and address the area of caregiver concern to provide an ultimate rehabilitation to the person with illness. Even though a number of instruments are available for the CGs, the assessment of burden has become a challenging task for most researchers because cultural, ethical, religious, and other personal values may influence perceptions of meaning and consequences of burden.[14-16]

Conclusions

In the present study, a 25 items CBS-IP was developed to assess the burden in caregivers of person with neurologically illness. The study established the face validity, content validity and construct validity of the CBS-IP. The results of this study confirmed the usefulness of the content validation process to develop valid and reliable content for scale in medical research.

Designing CBS-IP could be considered as an essential step towards focusing on population with neurological illness and their caregivers in India because this group of people deserves more consideration and this disease is worthy of more investment. The merit of the CBS-IP multidimensional scale is that it will allows the evaluation of responsiveness for intervention. Multidimensional instruments are particularly useful for investigating questions in the complex areas of burden. The scores of CBS-IP will help to target the specific area, and also give direction to the interventions needed to reduce burden.

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Conflicts of interest

There are no conflicts of interest.

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