

An Indian Adaptation of the Involvement Evaluation Questionnaire: Similarities and Differences in Assessment of Caregiver Burden

评估照顾者负担的情感参与评估问卷：欧洲版与印地语译本的异同

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Abstract

Objectives: The Involvement Evaluation Questionnaire (IEQ) is a comprehensive, conceptually valid and reliable means of assessing caregiver burden. However, its psychometric properties have rarely been examined in non-European settings. The aim of the present study was to evaluate the psychometric properties of an Indian translation of the IEQ (Hindi-IEQ).

Methods: The European Union (English) version of IEQ was translated into Hindi and reviewed by a group of experts and caregivers for translation accuracy, cultural appropriateness, and for relevance and acceptability of items and constructs. The Hindi-IEQ was then administered to 162 primary caregivers of patients with severe mental illnesses. Eighteen caregivers completed both the English and Hindi versions to check the level of agreement between them. Another 27 completed the Hindi-IEQ twice, a week apart, to evaluate its test-retest reliability. Factor structure of the Hindi-IEQ was examined using an exploratory, principal components and factor analysis.

Results: Pearson's correlation coefficients were significant for 24 items, while intraclass correlation coefficients were significant for 28 of the 31 items ($p < 0.05$), indicating a satisfactory level of agreement between the Hindi and English versions. Test-retest reliability for all items of the Hindi-IEQ was adequate, with kappa values ranging from 0.46 to 0.95 and intraclass correlation coefficients from 0.76 to 1.00. Internal consistency (Cronbach's alpha = 0.89) and the split-half reliability (Spearman-Brown coefficient = 0.68) of the Hindi-IEQ were also satisfactory. However, several differences were noted in the factor structure and distribution of scores of the Hindi-IEQ, which were quite unlike that of the European Union version.

Conclusions: The similarities and differences between the 2 versions of the IEQ indicated that sociocultural factors could influence assessment of caregiver burden across different cultures.

Key words: Caregivers; Cross-cultural comparison; Stress, psychological

摘要

目的：情感参与评估问卷能对照顾者的负担作出全面、概念正确和可靠的评估。不过，在欧洲以外地区，有关问卷之心理测量特质的研究则寥寥可数。因此，本研究以问卷的印地语译本检视其心理测量特质。

方法：研究把问卷欧洲版译成印地语，并经专家和照顾者对译本的准确度、文化适度，以及研究项目和构念的相关性和可受性作出评核后，向162名重症精神病患者的照顾者进行问卷调查。当中共18名照顾者完成英语和印地语版本的调查，以评核两者的一致性。另外27名照顾者完成首次问卷后，相隔1星期后进行第2次问卷调查，以评估其重测信度。研究也透过探索性主成分及因素分析，检视印地语译本的因素结构。

结果：问卷共包括31个项目，当中24项的Pearson相关系数和28项的组内相关系数均呈统计学意义 ($p < 0.05$)，显示问卷两个版本的一致度令人满意。此外，印地语译本内所有项目不论其再测信度 (kappa值介乎0.46-0.95)、组内相关系数 (0.76-0.99)、内部一致性 (Cronbach's alpha = 0.89) 和分半信度 (Spearman-Brown 系数 = 0.68) 均达良好水平；然而，其部份因素结构和得分的分布情况跟欧洲版本有所不同。

结论：情感参与评估问卷两个版本之异同，显示社会文化因素可影响对不同地方照顾者的负担评估。

关键词：照顾者、跨文化比较、心理压力

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Introduction

Caregiver burden has been defined by Platt as “*the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient’s significant others (e.g. members of the household and / or the family)*”.¹ Over the past 5 or 6 decades, research on caregiver burden has progressed from simple enumeration of problems faced to more elaborative and conceptually driven exploratory studies.² Newer conceptual models such as the stress-appraisal-coping paradigm, the role theory, and the systems approach have been applied to examine the experience of caregiving and different facets of the caregiver burden.³

The number of different instruments to assess caregiver burden has also increased several folds in recent years. While earlier reviews on this subject had identified about 2 dozens of such scales,^{1,3} a recent systematic review yielded 74 different instruments with adequate psychometric properties, which had been used to measure caregiver burden.⁴ These scales differed in terms of their format (interview vs. self-report), purpose (generic vs. specific scales for individual disorders), and content (covering all areas of burden vs. focusing on 1 area, e.g. economic burden).^{1,3-5} Although many of these scales have been translated into other languages, 2 of them, viz. the Zarit Burden Interview and the Involvement Evaluation Questionnaire (IEQ) have undergone the most extensive testing for their cross-cultural applicability.^{4,6-8} The Zarit Burden Interview is a self-report scale that has more commonly targeted caregivers of patients with dementia, while the IEQ has more often been used in caregivers of those with schizophrenia or mood disorders.^{4,9}

India has a long history of burden research, with several studies carried out among family caregivers in different parts of the country at various points in time.¹⁰ Devised by Pai and Kapur,¹¹ the Family Burden Interview (FBI) Schedule has been the instrument most commonly used to assess caregiver burden. This scale was based on the traditional distinction between objective and subjective burden, wherein objective burden refers to the objective /

tangible consequences of the patient’s illness on the family, while the caregiver’s own perception of the impact of caring is referred to as subjective burden.¹² However, the categorisation of burden into objective and subjective aspects has been criticised on the grounds that these overlapping dimensions are difficult to operationalise and assess.¹³ Moreover, the primary focus of the FBI Schedule is on objective burden, and its assessment of subjective burden is relatively inadequate.¹ Finally, although the FBI Schedule has been used in developing countries quite often, its psychometric properties have seldom been examined.^{1,14,15}

In contrast to the FBI, the IEQ is based on the stress-appraisal-coping model of caregiver burden, which is one of the dominant paradigms for conceptualising such burden.^{4,7,9} The IEQ was developed to assess caregiver burden or the ‘consequences of caregiving’ (a more neutral term for burden preferred by the authors). It relies on the caregiver’s perceptions to assess burden without distinguishing between its objective and subjective aspects. The IEQ has been extensively tested and has proved to be a comprehensive, conceptually valid, and reliable means of determining the consequences of providing care for a mentally ill family member.^{7,9} The instrument has also been translated into several European languages. Cross-cultural applicability of some of these versions was examined in 5 different European sites as a component of the European Psychiatric Services: Inputs Linked to Outcome Domains and Needs (EPSILON) study.^{7,9,16} Although the internal consistency, test-retest reliability, and factorial validity of the instrument were satisfactory in a majority of these sites,⁹ the results often varied (possibly due to sociocultural differences).⁷ More recently, a study from Hong Kong found the psychometric properties of a Chinese version of the IEQ to be adequate for use among the local population.⁸ Apart from a Hong Kong study among caregivers of patients with schizophrenia,¹⁷ the IEQ has also been used among corresponding populations in Malawi¹⁸ and in Kuwait.¹⁹ This makes it ideally suited for adaptation and use in other Asian or African languages. An Indian adaptation of the IEQ would also fill the current local void for a newer instrument to measure caregiver burden, because of problems with the FBI. These considerations prompted us to develop a version of the IEQ in Hindi (the local language) [Hindi-IEQ], and examine its psychometric properties, particularly its factor structure, among Indian caregivers of persons with severe mental illness.

Methods

This study was conducted in the psychiatry department of a multi-specialty hospital catering to a large section of the population of North India.

Approval and Recruitment

The study protocol was approved by the research and ethics committees of the institute where it was conducted. All participants were recruited from the outpatient clinic of the

department during the period of January 2010 to August 2010. Purposive sampling was used, in which all participants fulfilling the selection criteria were inducted after obtaining proper written informed consent. Other ethical safeguards were also maintained during the conduct of the study.

Involvement Evaluation Questionnaire – European Union Version

Originally developed in the Netherlands, the IEQ consisted of a series of interconnected domains that represent the possible consequences of caring for a family member with severe mental illness.^{4,6,7} The instrument has been refined over several versions and translated into a number of languages. The psychometric properties of the scale in terms of internal consistency (Cronbach's alpha = 0.74-0.90), test-retest reliability (intraclass correlation coefficients [ICCs] = 0.83-0.90), coverage and comprehensiveness, and ease of use had all proved to be satisfactory across different studies.^{7,9} Factor analyses have revealed 4 factors or caregiving domains, namely tension, supervision, worrying, and urging.¹⁶ The cross-cultural applicability of the IEQ European Union version (IEQ-EU) [in English] also appears to be largely adequate, although some reservations have been expressed in this regard.^{7,8,16}

The version chosen for this study was the one used in the EPSILON study, which is the one usually referred to when using the term IEQ-EU.⁹ Its core module, which assesses caregiving consequences, consists of 31 items. Among these, 27 were grouped into 4 subscales (2 items appeared in > 1 subscale), namely: tension (9 items referring to the strained interpersonal atmosphere between patients and relatives), worrying (6 items relating to concerns about the patient's safety and future), urging (8 items that covered activation and motivational aspects of caregiving), and supervision (6 items that included tasks related to managing the patient's behavioural problems). The remaining 4 items are: (1) the ability to pursue their own activities; (2) getting used to the patient's problems; (3) the ability to cope with the patient's problems; and (4) change in emotional relationship. For research use, all items were scored on 5-point Likert scales. In addition to the 4 subscale scores, a 27-item total IEQ-EU score is usually calculated. The scale is meant to cover a 4-week period prior to the assessment, and is primarily used among caregivers who had more than 1 hour's contact with the patient during that period. It is meant to be used as a self-administered questionnaire to be completed by the caregiver, but can also be administered as a structured telephone interview. The core module took about 10 minutes to complete.

Involvement Evaluation Questionnaire – Hindi Translation

The IEQ-EU was translated into Hindi by bilingual mental health professionals, using standard translation-back-translation methodology.^{8,20} Following this, the initial Hindi version was reviewed for accuracy of translation, cultural appropriateness, and the relevance of items and constructs

by 5 primary caregivers of patients with schizophrenia, 3 psychiatrists, 1 clinical psychologist, and 1 social worker. All the suggestions made by this group were incorporated into a pre-final version of the Hindi-IEQ, which was administered to a second set of 5 primary caregivers to test its acceptability. This exercise resulted in the final version, which was subsequently used to evaluate the psychometric properties and factor structure of the Hindi-IEQ.

Participants

The Hindi-IEQ was administered to 162 primary caregivers of patients with severe mental illnesses (schizophrenia, other psychotic disorders, bipolar affective disorder, recurrent depressive disorder, and obsessive-compulsive disorder).

All the patients were diagnosed according to the ICD-10 criteria after detailed semi-structured assessments by a trainee and a consultant psychiatrist. In addition, they had to be aged 18 to 60 years, had an illness duration of > 1 year, and were living with relatives. Patients with organic brain disorders, substance abuse / dependence (except nicotine), or those with chronic physical disorders were excluded. Primary caregivers were healthy adult relatives who were living with the patients for ≥ 1 year prior to assessment. Only those judged to be intimately involved in the patient's care were included. This involved looking after the patient's daily needs, supervising medications, bringing the patient to the hospital, staying with the patient during hospitalisation, and liaising with the hospital staff.

Assessment of Psychometric Properties

All 162 caregivers completed the Hindi-IEQ on their own; of these, 18 also completed the English version to check the level of agreement between these 2 versions. Another 27 completed the Hindi-IEQ twice (1 week apart) to evaluate the test-retest reliability of this version. All items were rated on a 5-point scale (0 = never; 1 = sometimes; 2 = regularly; 3 = often; 4 = always). The factor structure of the Hindi-IEQ was examined among all 162 caregivers using an exploratory, principal components and factor analysis.

Statistical Analyses

Statistical analyses were carried out using the SPSS 14 (SPSS, Chicago [IL], US). Frequencies, percentages, means, and standard deviations were used to describe the data. Agreement between the Hindi and English versions was examined using the ICCs and Pearson's correlation coefficients (r). The test-retest reliability of the Hindi-IEQ was evaluated by estimating Cohen's kappa values and ICCs. Cronbach's alpha was used to examine the internal consistency, and the Spearman-Brown coefficient to determine the split-half reliability of the entire Hindi-IEQ scale. Principal components analysis using orthogonal rotation with the varimax technique was employed to explore the factor structure of the Hindi-IEQ. To determine the optimal number of the factors, initially only those with an eigenvalue of > 1 were included and loadings that were ≥ 0.4 were identified as significant to render the extracted

Table 1. Profile of participants.*

Characteristic	Patients (n = 162)	Caregivers (n = 162)	X ² / t test values
Age (years)	39 ± 15	47 ± 13	t = 5.23 [†]
No. (%) of females	82 (51%)	54 (33%)	X ² = 9.93 [‡]
Currently married	101 (62%)	137 (85%)	X ² = 20.51 [†]
Years of schooling	11 ± 5	12 ± 3	t = 3.65 [§]
Occupation			
Employed	74 (46%)	122 (75%)	X ² = 21.81 [†] (working vs. not working)
Unemployed	27 (17%)	2 (1%)	
Housewife / household	61 (38%)	38 (23%)	
Monthly family income (in Rupees)	17,492 (16,734)		-
Urban residence	101 (62%)		-
Age of onset of illness (years)	30 ± 17	-	-
Duration of illness (years)	11 ± 9	-	-
Diagnosis			
Schizophrenia	69 (43%)	-	-
Other psychotic disorders	17 (10%)	-	-
Bipolar disorder	43 (26%)	-	-
Recurrent depressive disorder	27 (17%)	-	-
Obsessive-compulsive disorder	6 (4%)	-	-
Duration of caregiving (years)	-	9.3 ± 8.5	-
Time spent in caregiving (hours / day)	-	4.6 ± 3.7	-
Relationship with the patient			
Parent	-	52 (33%)	-
Spouse	-	71 (44%)	-
Sibling	-	20 (12%)	-
Others	-	19 (12%)	-

* Data are shown as mean ± standard deviation and No. (%).

[†] p < 0.0001.

[‡] p < 0.01.

[§] p < 0.001.

factors meaningful and interpretable. When any of the items loaded ≥ 0.4 on ≥ 2 factors, they were assigned to the factor with the highest loading. The aim was to obtain a factor structure, which retained the maximum number of variables and explained the maximum variance, with each factor having a loading of at least 3 items. The final factor solution was worked out by conducting multiple analyses based on differing numbers of factors, by constructing scree plots and by referring to previous literature.

Results

Profile of the Sample

Demographic and clinical characteristics of the 162 patients and their primary caregivers are summarised in Table 1. The patients were in their late thirties when assessed, and had been ill for a mean (standard deviation [SD]) of about 11 (9) years. The sample consisted of an equal proportion of those with schizophrenia and mood disorder (43% each); this

diagnostic distribution was probably the main reason for the almost equal numbers of males and females. A certain number of the patients were married (62%), educated, and either employed (46%) or engaged in household duties (38%). As expected, caregivers were significantly different from patients in several aspects, being older; and more likely to be male, better educated, married, and working. They had cared for the patients for almost the entire duration of the illness, and spent a mean of 4.6 (SD = 3.7) hours per day in doing so. Regarding the caregivers in schizophrenia group, 28 (41%) were spouses, 26 (38%) parents, and 15 (22%) other relatives; the corresponding figures in the mood disorder group were 35 (50%), 16 (23%), and 19 (27%). These differences between the groups were not significant (Chi-square value = 4.41; p = 0.11). Nevertheless, this distribution could account for the fact that though spousal caregivers formed the largest single category (44%), one-third of the total sample of caregivers were parents of the patients.

Psychometric Properties

Agreement between Hindi and English Versions

Pearson's correlation coefficients and ICCs for scores on the Hindi and English versions among the 18 caregivers who completed both were statistically significant ($p < 0.05$) for most items. This was the case for 24 out of the 31 items for correlation coefficients, and 28 out of the 31 items for ICCs. This indicated that there was a satisfactory level of agreement between the English and Hindi versions. Results are shown in Table 2.

Test-retest Reliability

For all 31 items, both the kappa values (range, 0.46-0.95) and ICC values (range, 0.76-1.00) were significant in the sample of 27 caregivers who completed the Hindi-IEQ questionnaire on 2 occasions, 1 week apart, suggesting adequate test-retest reliability.

Internal Consistency and Split-half Reliability

Cronbach's alpha (as a measure of internal consistency) was 0.89, and the Spearman-Brown coefficient (for assessing split-half reliability) was 0.68; both being more than adequate for the Hindi-IEQ.

Factor Structure

Bartlett's test of sphericity was used to test the null hypothesis that the variables were uncorrelated in the population; the Chi-square statistic for the current data was 2323.27, which was highly significant ($p < 0.001$). The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.87, suggesting that factor analysis was an appropriate method for analysing the current data. In the initial analyses, factor solutions with 3, 4 and 5 factors were quite similar and all provided good fit for the data. The scree plot tailed off at the 3- to 4-factor level, indicating 3- or 4-factor solutions to be optimal. A 4-factor solution was also in keeping with all the previous factor analytic studies of the IEQ.^{4,6-8} While the 4-factor model accounted for 29 of the 31 items, only 1 item was left unaccounted for in the 5-factor solution. The 4-factor model explained 51% of the variance, while the 5-factor solution explained 55%. In view of the tailing of the scree plot and existing literature on the factor structure of the IEQ-EU, only the 4-factor solution was eventually retained.

The rotated factor matrix and item loading of the 4-factor model is depicted in Table 3. It shows that the factor structure of the Hindi-IEQ differed from the IEQ-EU in several important ways. First, there were more than 27 items loaded onto the 4-factor version of the Hindi-IEQ. Second, differences in loading from the IEQ-EU were noted for 10 items in the 4-factor model of the Hindi-IEQ. Finally, and perhaps most significantly, there was a substantial overlap between the worrying and urging factors in terms of items that loaded onto these factors. Hence, they were re-labelled as worrying-urging factors I and II in the Hindi-IEQ.

Scores of Subscales

To allow comparison with the IEQ-EU, total and subscale

scores were estimated using the 27-item total score of the original IEQ-EU format. Mean (SD) scores among caregivers of this study were as follows: total IEQ = 38.3 (19.8), urging subscale = 16.5 (1.0), worrying subscale = 10.6 (7.0), tension subscale = 7.0 (6.6), and supervision subscale = 5.8 (5.1). Comparisons of these scores with pooled estimates of IEQ-EU scores from the EPSILON study⁹ revealed that total IEQ scores of the latter study were significantly higher than those obtained in the present study ($p < 0.001$). Similarly, scores on the subscales of worrying, tension, and supervision were also significantly higher in the EPSILON study ($p < 0.001$), while there were no significant differences in the urging subscale scores between the 2 studies.

Another difference between the 2 versions was the significant associations obtained between scores on various subscales of the Hindi-IEQ. These included significant correlations between scores on the tension subscale and the other 3 subscales, i.e. the 2 worrying-urging subscales ($r = 0.25$, $p < 0.01$; $r = 0.47$, $p < 0.001$) and the supervision subscale ($r = 0.35$, $p < 0.001$). Significant correlations were also observed between scores on the 2 worrying-urging subscales ($r = 0.58$, $p < 0.001$), and between scores on 1 worrying-urging subscale and the supervision subscale ($r = 0.35$, $p < 0.01$).

Demographic and Clinical Correlates of Total Scores

Only 2 variables were significantly associated with the total Hindi-IEQ scores. Younger patients demonstrated a significant association with higher total scores ($r = 0.17$; $p < 0.05$), while the time spent with the patient each day by the caregiver was positively associated with higher total scores ($r = 0.24$; $p < 0.01$). None of the other variables demonstrated any consistent associations with the Hindi-IEQ scores. In particular, there were no significant differences between total and subscale scores of the 2 main diagnostic groups (schizophrenia and mood disorders). For comparison, Hindi-IEQ scores in the 2 diagnostic groups are depicted in Table 4.

Discussion

The IEQ was chosen for adaptation because it is a simple, brief, and an easy-to-use self-administered measure of caregiver burden. It has a sound conceptual basis and has demonstrated adequate psychometric properties on repeated testing.^{7,9,16} It has also been used in developing countries, though its validity, reliability and factor structure in such settings have only been evaluated in a single study among Chinese caregivers of patients with schizophrenia.⁸

The EPSILON study was conducted to examine the cross-cultural validity and applicability of 5 key research instruments across 5 European sites located in different countries. Results regarding the IEQ-EU demonstrated that versions in different languages covered the same

Table 2. Psychometric properties of the Hindi version of Involvement Evaluation Questionnaire.

Item	Test-retest reliability of the Hindi version		Agreement between the Hindi and English versions	
	Cohen's kappa value	Intraclass correlation coefficient	Pearson's correlation coefficient	Intraclass correlation coefficient
1. Has your relative / friend disturbed your sleep?	0.95*	0.96*	0.68†	0.81*
2. Has the atmosphere been strained between you both, as a result of your relative / friend's behaviour?	0.69*	0.79*	0.62†	0.76†
3. Has your relative / friend caused a quarrel?	0.55*	0.81*	0.48‡	0.65‡
4. Have you been annoyed by your relative / friend's behaviour?	0.46*	0.79*	0.58‡	0.73†
5. Have you heard from others that they have been annoyed by your relative / friend's behaviour?	0.67*	0.91*	0.15	0.24
6. Have you felt threatened by your relative / friend?	0.71*	0.94*	0.84*	0.89*
7. Have you thought of moving out, as a result of your relative / friend's behaviour?	0.83*	0.89*	0.85*	0.92*
8. Have you worried about your own future?	0.49*	0.92*	0.40	0.57‡
9. Have your relative / friend's mental health problems been a burden to you?	0.79*	0.98*	0.81*	0.89*
10. Have you guarded your relative / friend from committing dangerous acts?	0.70*	0.92*	0.59†	0.74†
11. Have you guarded your relative / friend from self-inflicted harm?	0.88*	0.99*	0.62†	0.77†
12. Have you ensured that your relative / friend received sufficient sleep?	0.54*	0.88*	0.82*	0.90*
13. Have you guarded your relative / friend from drinking too much alcohol?	0.88*	1.00*	0.85*	0.92*
14. Have you guarded your relative / friend from taking illegal drugs?	0.84*	0.98*	0.85*	0.92*
15. Have you worried about your relative / friend's safety?	0.56*	0.91*	0.41	0.58‡
16. Have you worried about the kind of help / treatment your relative / friend is receiving?	0.77*	0.96*	0.50‡	0.66‡
17. Have you worried about your relative / friend's general health?	0.84*	0.94*	0.68†	0.77†
18. Have you worried about how your relative / friend would manage financially if you were no longer able to help?	0.71*	0.89*	0.46	0.63‡
19. Have you worried about your relative / friend's future?	0.84*	0.98*	0.28	0.44
20. Have you encouraged your relative / friend to take proper care of herself / himself?	0.75*	0.85*	0.82*	0.90*
21. Have you helped your relative / friend to take proper care of herself / himself?	0.78*	0.98*	0.75*	0.86*
22. Have you encouraged your relative / friend to eat enough?	0.72*	0.96*	0.17	0.24
23. Have you encouraged your relative / friend to undertake some kind of activity?	0.90*	0.96*	0.39	0.56‡
24. Have you accompanied your relative / friend on some kind of outside activity, because he / she did not dare to go alone?	0.85*	0.99*	0.80*	0.89*
25. Have you ensured that your relative / friend has taken the required medicine?	0.68*	0.86*	0.75*	0.85*
26. Have you carried out tasks normally done by your relative / friend?	0.86*	0.92*	0.67†	0.80*
27. How often during the past 4 weeks have you encouraged your relative / friend to get up in the morning?	0.86*	0.92*	0.50‡	0.67‡
28. Have you been able to pursue your own activities and interests?	0.67*	0.76*	0.86*	0.99*
29. Have you got used to your relative / friend's mental problems?	0.89*	0.97*	0.80*	0.95*
30. How often have you felt able to cope with your relative / friend's mental health problems?	0.69*	0.93*	0.86*	0.99*
31. Has your relationship with your relative / friend changed since the onset of the mental health problems?	0.83*	0.93*	0.73*	0.93*

* $p < 0.001$.† $p < 0.01$.‡ $p < 0.05$.

Table 3. Factor structure of the Hindi version of Involvement Evaluation Questionnaire: the 4-factor solution.*

Item	Tension	Worrying – urging I	Worrying – urging II	Supervision
Eigenvalues	5.75	4.64	3.01	2.50
Variance explained	18.5%	15.0%	9.7%	8.1%
Item loadings				
1. Has your relative / friend disturbed your sleep?	0.61	-	-	-
2. Has the atmosphere been strained between you both, as a result of your relative / friend's behaviour?	0.65	-	-	-
3. Has your relative / friend caused a quarrel?	0.75	-	-	-
4. Have you been annoyed by your relative / friend's behaviour?	0.74	-	-	-
5. Have you heard from others that they have been annoyed by your relative / friend's behaviour?	0.76	-	-	-
6. Have you felt threatened by your relative / friend?	0.66	-	-	-
7. Have you thought of moving out, as a result of your relative / friend's behaviour?	0.76	-	-	-
8. Have you worried about your own future?	0.46	-	0.53	-
9. Have your relative / friend's mental health problems been a burden to you?	0.68	-	-	-
10. Have you guarded your relative / friend from committing dangerous acts?	0.67	-	-	-
11. Have you guarded your relative / friend from self-inflicted harm?	-	-	-	0.59
12. Have you ensured that your relative / friend received sufficient sleep?	-	0.61	-	-
13. Have you guarded your relative / friend from drinking too much alcohol?	-	-	-	0.88
14. Have you guarded your relative / friend from taking illegal drugs?	-	-	-	0.87
15. Have you worried about your relative / friend's safety?	-	-	0.45	-
16. Have you worried about the kind of help / treatment your relative / friend is receiving?	-	-	0.47	-
17. Have you worried about your relative / friend's general health?	-	0.72	-	-
18. Have you worried about how your relative / friend would manage financially if you were no longer able to help?	-	-	-	-
19. Have you worried about your relative / friend's future?	-	0.45	-	-
20. Have you encouraged your relative / friend to take proper care of herself / himself?	-	0.65	-	-
21. Have you helped your relative / friend to take proper care of herself / himself?	-	0.70	-	-
22. Have you encouraged your relative / friend to eat enough?	-	0.70	-	-
23. Have you encouraged your relative / friend to undertake some kind of activity?	-	0.67	-	-
24. Have you accompanied your relative / friend on some kind of outside activity, because he / she did not dare to go alone	-	-	0.68	-
25. Have you ensured that your relative / friend has taken the required medicine?	-	0.59	-	-
26. Have you carried out tasks normally done by your relative / friend?	-	-	0.64	-
27. How often during the past 4 weeks have you encouraged your relative / friend to get up in the morning?	-	-	0.60	-
28. Have you been able to pursue your own activities and interests?	-	0.51	-	-
29. Have you got used to your relative / friend's mental problems?	-	-	-	-
30. How often have you felt able to cope with your relative / friend's mental health problems?	-	0.65	-	-
31. Has your relationship with your relative / friend changed since the onset of the mental health problems?	0.47	-	-	-

* Principal components analysis with varimax rotation; only items with factor loading of ≥ 0.4 are shown. Values in bold represent item loadings of each factor.

Table 4. Subscale scores of the Hindi version of Involvement Evaluation Questionnaire.

Subscale	Total sample (n = 162)	Schizophrenia (n = 69)	Mood disorder (n = 70)	t Test (p) values	Mann-Whitney U (p) value
Tension	6.07 (5.53)	5.17 (5.53)	5.89 (6.29)	-	2300 (0.62)
Worrying – urging I	24.52 (10.54)	23.11 (10.13)	25.68 (11.41)	1.39 (0.16)	-
Worrying – urging II	9.14 (5.72)	8.72 (5.65)	9.51 (5.87)	0.80 (0.42)	-
Supervision	1.87 (3.34)	1.20 (2.80)	2.41 (3.82)	-	2089 (0.11)

caregiving domains in all the 5 sites.⁷ Internal consistency and reliability of the IEQ-EU were adequate in 4 of these 5 sites.⁹ The underlying 4-factor structure of the IEQ also proved to be stable across all sites, and was identical to the original Dutch IEQ. At the same time, there was considerable variation in total and subscale scores across the sites. These differences persisted despite adjusting for patient and caregiver characteristics known to influence IEQ scores. Although other confounding influences could not be completely ruled out, the authors considered the possibility that the differences between sites could be attributed to cultural factors, or differences in provision of mental health care services. They therefore cautioned that other translated versions of the IEQ need to develop their own norms suited to their local culture.⁷

The results of the current study appear to echo these concerns by revealing patterns of similarities and differences between the Hindi and the EU versions of the IEQ. Thus, much like its progenitor, the Hindi-IEQ had sound psychometric properties. There was a satisfactory level of agreement between the translated and original versions on a majority of the items. Test-retest reliability statistics (kappa values and ICCs) of individual items of the Hindi-IEQ were significant, and well within the range found in the EPSILON sites,⁹ as well as those found in the sole Chinese study on psychometric properties of the IEQ.⁸ Similarly, internal consistency determined by Cronbach's alpha was equivalent to earlier studies,^{7,16} whereas split-half reliability of the scale was similar to that found in the Chinese study.⁸ Thus, the benchmark for substantial reliability²¹ was attained by the Hindi-IEQ in all these instances. Moreover, these results were obtained for both psychosis (mainly schizophrenia) and mood disorder groups. Notably, the patient sample of the current study also contained a substantial number of patients with mood disorders. This was a somewhat unique feature of this study, since the IEQ-EU has been primarily validated among caregivers of patients with schizophrenia, and only the original Dutch version of the IEQ was validated among caregivers of patients with depressive disorders.² Another similarity was the positive association between hours of caregiving and the Hindi-IEQ scores, which was akin to the finding of higher IEQ-EU scores among caregivers with greater contact with patients in the EPSILON study.⁷ However, contrary to previous reports of higher IEQ scores among older patients,^{7,16} in the current study younger patient's age

was linked to higher Hindi-IEQ scores. Then again, studies of caregiver burden, which employed different measures of burden, have highlighted the inconsistent effect of patient age on burden, with both higher and lower levels of caregiver burden being found in younger patients.¹² Accordingly, other differences between the Hindi-IEQ and the IEQ-EU with regard to distribution of scores and underlying factor structure were more notable. Comparisons of mean scores with some of the earlier studies of the IEQ-EU revealed several important differences. Firstly, in the present study scores on the urging subscale were greater than those of the worrying subscale. Consequently, the rank order of mean scores (urging > worrying > tension > supervision) was somewhat different from most of the earlier studies with the IEQ.^{2,9,7,17} Scores on many of the subscales of the Hindi-IEQ demonstrated significant correlations with each other, which was unlike the IEQ, in which only the 2 interpersonal domains correlated with each other, as did the 2 behavioural domains.¹⁶ Finally, total and subscale IEQ scores obtained in this study were significantly lower than the pooled estimates found in the EPSILON study,⁷ except in the case of the urging subscale scores. However, these differences did not immediately imply a European-Asian divide, since there were also considerable variations in scores across different sites in the EPSILON study, as well as between the few Asian studies of the IEQ. A Kuwaiti study¹⁹ using the IEQ-EU obtained scores that were significantly higher than that in the current study, though the rank order of subscale scores was similar. On the other hand, in the study from Hong Kong¹⁷ the rank order of subscale scores was different from the current study, while mean scores appeared to be lower than in the present study. The differences in factor structure of the Hindi-IEQ were even more pronounced than the variations in distribution of scores. Rather than the consistently replicated 4-factor structure of the IEQ,^{7,8,16} in the current study 3-, 4- and 5-factor solutions all seemed to provide good fit for the data. Even though a 4-factor solution was eventually retained for the present study, there were quite a few differences between the Hindi-IEQ and the IEQ-EU. These included differences in many of the item loadings, and more importantly, a great degree of overlap between the worrying and urging factors observed in the current study. All these differences indicated that in the present study, the urging dimension of caregiver burden was much more prominent than in most of the earlier studies.^{2,7,9,17}

The reasons for these differences were not clear. Although the scores were not adjusted for patient and caregiver characteristics, it was unlikely these factors had contributed much to the different pattern of scores of the Hindi-IEQ, as they had very little influence on the scores in the present study, and in most earlier ones.^{7,17} Many of the other studies had been conducted among caregivers of patients with schizophrenia,^{8,17,19} whereas a large proportion of the current patient sample had mood disorders. In this study, however, scores of the mood disorder group did not differ significantly from those of the schizophrenia group, indicating that diagnostic distribution was not the reason for the differences observed. Therefore, the role of sociocultural differences needs to be considered, lest they account for the variations in scores and factor structure of the Hindi-IEQ. One of the mediating factors proposed by the EPSILON study investigators was the disparity in the quality and quantity of mental health services between countries.⁷ However, according to this hypothesis,²² inadequate levels of service provision (the expected norm in low-income countries like India) should lead to comparatively higher levels of caregiver burden, rather than the lower levels that were actually found. Consequently, other cultural factors, particularly culturally influenced differences in perception of caregiver burden, may need to be invoked to explain these variations.

Historically, and in contrast to their western counterparts, Indian caregivers have never been systematically excluded from the treatment of people with mental illness. Thus, a large part of the mental health care has always taken place in the community with the family as the primary care provider. Long-term studies have shown that caregivers are called upon to provide support to their patients not only during the period of the acute illness, but also in the aftercare and recovery process, and that such care extended to housing and financial support to those not employed.^{10,23,24} Moreover, as noted by several authors, Indian patients not only tend to live with natural caregivers, but both research evidence and clinical practice suggest that the primary kin network has a pre-eminent role in virtually all decisions regarding treatment.¹⁰ In common with other ethnic groups, filial obligations (e.g. filial piety) and other forms of family responsibility (e.g. familism) also appear to influence the process of caregiving among Indian families.^{25,26} Apart from these expectations regarding relations and obligations of kinship, other factors that keep the Indian family involved and committed to its caregiving role have also been proposed. These include a culturally determined view of the world, an explanatory model of mental illness that is benign, as well as cultural variations in the expression of emotions.²⁷ Moreover, this natural preference of families to be involved in the care of their mentally ill is further reinforced by the woefully inadequate mental health infrastructure and the lack of facilities and personnel, which virtually compel families to become sole caregivers of the mentally ill.^{10,23} Accordingly, it is not surprising that ethnographic studies have noted that

relatives of Indian patients have to perform a number of care-related tasks, ordinarily carried out by mental health professionals elsewhere. By assuming many of the roles fulfilled by mental health personnel, Indian families appear to maintain considerable control over many aspects of the treatment process, e.g. defining the disorder, outpatient consultations, record-keeping, admissions, inpatient care, discharge, and aftercare.²⁸ It is possible that this over-involvement of Indian caregivers in the treatment process could explain the predominance of the urging dimension, and its overlap with other dimensions as found in this study. However, such explanations are essentially speculative, and remain so till studies specifically designed to test them are conducted.

The results of the current study need to be viewed with some caution because of its methodological limitations. These included the fact that all patients were hospital attendees, which restricts the ability to generalise the results to other groups, e.g. community-based patients. The predominance of male caregivers was also unusual, and could be an artefact of treatment-seeking. The Indian literature in this regard is somewhat inconsistent; though female predominate as caregivers in most of the studies, there is a preponderance of male caregivers in some of the others.²⁹ Although the sample size ($n = 162$) was adequate for factor analysis, being more than 5 times the number of items, sample sizes for agreement between English and Hindi versions ($n = 18$), and test-retest reliability ($n = 27$) were rather small. Thus, results on the latter parameters need replication among larger samples. Finally, the effects of several potential confounders such as social support, caregiver coping, patient and caregiver characteristics were neither explored nor controlled for.

Despite these problems, cultural variations in the IEQ as apprehended by its authors⁶ appear to have been replicated in this study. Accordingly, the need to modify adapted versions of the instrument to suit local cultural norms is further reiterated. Future research, which pays particular attention to this aspect, is more likely to yield a greater understanding of the caregiver burden in different cultures.

Declaration

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References

1. Platt S. Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. *Psychol Med* 1985;15:383-93.
2. van Wijngaarden B, Schene AH, Koeter MW. Family caregiving in depression: impact on caregivers' daily life, distress, and help seeking. *J Affect Disord* 2004;81:211-22.
3. Schene AH. Objective and subjective dimensions of family burden. Towards an integrative framework for research. *Soc Psychiatr Epidemiol* 1990;25:289-97.

4. Whalen KJ, Buchholz SW. The reliability, validity and feasibility of tools used to screen for caregiver burden: a systematic review. *JBIS Libr Syst Rev* 2009;32:1372-429.
5. Schene AH, Tessler RC, Gamache GM. Instruments measuring family or caregiver burden in severe mental illness. *Soc Psychiatry Psychiatr Epidemiol* 1994;29:228-40.
6. Chan TS, Lam LC, Chiu HF. Validation of the Chinese version of the Zarit Burden Interview. *Hong Kong J Psychiatry* 2005;15:9-13.
7. van Wijngaarden B, Schene A, Koeter M, Becker T, Knapp M, Knudsen HC, et al. People with schizophrenia in five countries: conceptual similarities and intercultural differences in family caregiving. *Schizophr Bull* 2003;29:573-86.
8. Tang VW, Leung SK, Lam LC. Validation of the Chinese version of the Involvement Evaluation Questionnaire. *Hong Kong J Psychiatry* 2008;18:6-14.
9. van Wijngaarden B, Schene AH, Koeter M, Vázquez-Barquero JL, Knudsen HC, Lasalvia A, et al. Caregiving in schizophrenia: development, internal consistency and reliability of the Involvement Evaluation Questionnaire — European version. *EPSILON Study 4. European Psychiatric Services: Inputs Linked to Outcome Domains and Needs. Br J Psychiatry Suppl* 2000;(39):S21-7.
10. Shankar R, Rao K. From burden to empowerment: the journey of family caregivers in India. In: Sartorius N, Leff J, López-Ibor JJ Jr, Okasha A, editors. *Families and mental disorder: from burden to empowerment*. Chichester, England: John Wiley & Sons Ltd; 2009: 259-90.
11. Pai S, Kapur RL. The burden on the family of a psychiatric patient: development of an assessment scale. *Br J Psychiatry* 1981;138:332-5.
12. Awad AG, Voruganti LN. The burden of schizophrenia on caregivers: a review. *Pharmacoeconomics* 2008;26:149-62.
13. Szmukler GI, Burgess P, Herrman H, Benson A, Colusa S, Bloch S. Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. *Soc Psychiatry Psychiatr Epidemiol* 1996;31:137-48.
14. Chien WT, Norman I. The validation and reliability of a Chinese version of the family burden interview schedule. *Nurs Res* 2004;53:314-22.
15. Siu BW, Yeung TM. Validation of the Cantonese version of Family Burden Interview Schedule on caregivers of patients with obsessive-compulsive disorder. *Hong Kong J Psychiatry* 2005;15:109-17.
16. Schene AH, van Wijngaarden B, Koeter MW. Family caregiving in schizophrenia: domains and distress. *Schizophr Bull* 1998;24:609-18.
17. Tang VW, Leung SK, Lam LC. Clinical correlates of the caregiving experience for Chinese caregivers of patients with schizophrenia. *Soc Psychiatry Psychiatr Epidemiol* 2008;43:720-6.
18. Sefasi A, Crumlish N, Samalani P, Kinsella A, O'Callaghan E, Chilale H. A little knowledge: caregiver burden in schizophrenia in Malawi. *Soc Psychiatry Psychiatr Epidemiol* 2008;43:160-4.
19. Zahid MA, Ohaeri JA. Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. *BMC Psychiatry* 2010;10:71.
20. Knudsen HC, Vázquez-Barquero JL, Welcher B, Gaite L, Becker T, Chisholm D, et al. Translation and cross-cultural adaptation of outcome measurements for schizophrenia. *EPSILON Study 2. European Psychiatric Services: Inputs Linked to Outcome Domains and Needs. Br J Psychiatry Suppl* 2000;(39):S8-14.
21. Schene AH, Koeter M, van Wijngaarden B, Knudsen HC, Leese M, Ruggeri M, et al. Methodology of the multi-site reliability study. *EPSILON Study 3. European Psychiatric Services: Inputs Linked to Outcome Domains and Needs. Br J Psychiatry Suppl* 2000;(39):S15-20.
22. Magliano L, Fadden G, Madianos M, de Almeida JM, Held T, Guarneri M, et al. Burden on the families of patients with schizophrenia: results of the BIOMED I study. *Soc Psychiatry Psychiatr Epidemiol* 1998;33:405-12.
23. Leggatt M. Families and mental health workers: the need for partnership. *World Psychiatry* 2002;1:52-4.
24. Shankar R, Menon MS. Development of a framework of intervention with families in the management of schizophrenia. *Psychosoc Rehabil J* 1993;16:75-91.
25. Gupta R, Pillai VK. Caregiver burden in South Asian families: a systems theory perspective. *J Ethnic Cult Divers Soc Work* 2000;9:41-53.
26. Gupta R, Rowe N, Pillai VK. Perceived caregiver burden in India: implications for social services. *J Women Soc Work* 2009;24:69-79.
27. Lefley HP. Discussion on family and social support system in the care of the mentally ill. In: Murthy RS, Burns BJ, editors. *Community Mental Health*. Bangalore: National Institute of Mental Health and Neurosciences; 1992: 289-95.
28. Nunley M. The involvement of families in Indian psychiatry. *Cult Med Psychiatry* 1998;22:317-53.
29. Chakrabarti S. Impact of schizophrenia on the family: the Indian perspective. In: Kulhara P, Avasthi A, Grover S, editors. *Schizophrenia: the Indian scene*. Chandigarh, India: Postgraduate Institute of Medical Education and Research; 2010: 215-62.